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ABSTRACT

This guidebook for parents of children with emotional or behavioral disorders includes descriptions of common diagnoses and therapies, information on programs and services, and a description of the roles of various mental health professionals. Introductory sections note the extent of the problem and the importance of parents not blaming themselves. The following seven sections provide specific information addressing the following questions of parents: "How do I know if my child might have an emotional or behavioral disorder?"; "What is an emotional or behavioral disorder?"; "What kinds of programs should I be looking for or considering?"; "What types of professionals work with children who have emotional or behavioral disorders?"; "What are some of the different philosophies and therapies?"; "What help can I expect from the school district for my child with an emotional or behavioral disorder?"; and "What is my role as a parent in planning services for my child?". Two concluding sections give a father's personal account and a look to the future. Appendices list relevant organizations, suggested additional reading, statewide parent organizations, parent training and information projects, and the System of Care Model of the federal Child and Adolescent Service System Program. (Includes 15 references) (DB)

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A GUIDEBOOK

for parents of children with emotional or behavioral disorders

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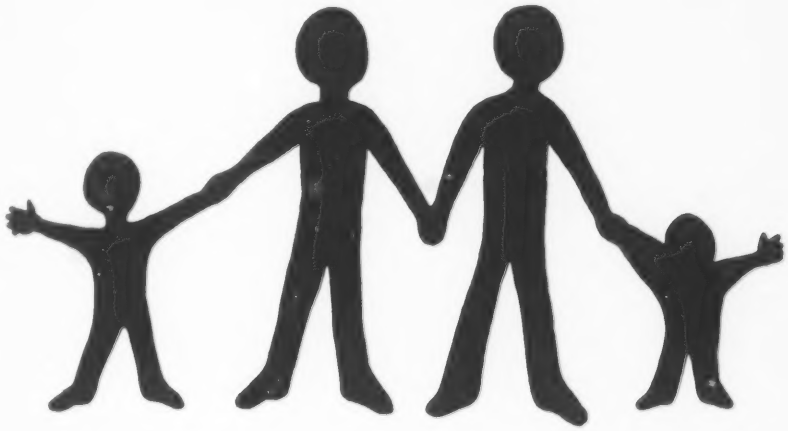

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A GUIDEBOOK

for parents of children with emotional or behavioral disorders

PACER Center, Inc.

A Guidebook for Parents of Children with Emotional or Behavioral Disorders

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Betty Binkard wrote the original version of this book in 1984.

A Guidebook for Parents of Children with Emotional or Behavioral Disorders is published in a Minnesota Edition, with listings of Minnesota service agencies and organizations, and in a National Edition.

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A Guidebook for Parents of Children with Emotional or Behavioral Disorders
was prepared by the
EBD Project of PACER Center
(Parent Advocacy Coalition
for Educational Rights).

PACER Center, a coalition of nineteen disability organizations, is founded on the concept of Parents Helping Parents and serves as the parent training and information center for Minnesota. PACER's mission is to improve and expand opportunities that enhance the quality of life for children and young adults with disabilities.

Introduction

When the first edition of this guidebook was written in 1984, there were not many positive statements to be made regarding the status of children and adolescents with serious emotional disorders (SED).

A 1981 study (Gould, et al.) estimated the prevalence rate of emotional problems in children and adolescents to be nearly twelve percent. The Gould figures, a compilation of a number of national studies, have been found to be perhaps a conservative estimate. The study suggests that:

- One child in eight (11.8 percent) has an emotional problem that limits his or her capacity to function.
- One child in twenty has a "severe emotional disorder."
- 15 to 20 percent of all children come from groups which are considered at higher risk of developing emotional disorders.

In her landmark book published in 1984, *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services,* Jane Knitzer of the Bank Street College of Education reported that two-thirds of all children with serious emotional disturbances in the United States were not receiving the services they needed. Many others received inadequate, inappropriate or unnecessarily restrictive care, sometimes in state hospitals. Further, although many of these children required the interventions of agencies and systems other than mental health (social services, health, special education, vocational, corrections, etc.), few states had any organized planning process for coordinating such services. (A second book by Jane Knitzer and the Bank Street College, *At the Schoolhouse Door: An Examination of Programs and Policies for Children With Behavioral and Emotional Problems,* 1990, highlights how some school and mental health agencies are now addressing the complex needs of children and adolescents with emotional or behavioral problems.)

Today, thanks in large measure to *Unclaimed Children* and to the advocacy efforts of parents and professionals, there are a number of state and federal initiatives to develop and coordinate services to children with serious emotional disorders (SED). The best known and most successful of such initiatives is a small federal program known as the Child and Adolescent Service System Program, or CASSP.

Launched in 1984 by the National Institute of Mental Health, CASSP developed a model of coordinated services that is child-centered, family-focused, and community-based: Children are to be served, whenever possible, in their own homes and communities, and families should receive the necessary support services to help them cope with the stresses of caring for their child. In order for systems to respond

appropriately to the needs of children, CASSP encourages that families be included in the planning and implementation of such service systems and that they act as a voice to state policymakers to support the development of appropriate services. The CASSP Project offers financial and technical assistance to states to implement a process directed to making necessary administrative, legislative, budgetary, and programmatic arrangements to develop and coordinate services to children with SED. Although all fifty states have now received CASSP grants, some states and communities had already undertaken system changes as a response to the issues outlined in *Unclaimed Children* and used their federal CASSP funds to expand those efforts.

One of the most promising initiatives for addressing the unmet mental health needs of children has come from families themselves. Parents, once blamed for their child's emotional difficulties, are assuming an increasing role in the development and implementation of an appropriate mental health program for their child.

Support Groups

Self-help groups are emerging to provide support and information to families who are dealing with extraordinarily difficult day-to-day problems or who are still struggling with feelings of shame or blame for their child's disorder.

Parent Networks

Currently, fifteen parent groups from different states have federal grants to aid in the development of statewide organizations or networks of parents whose children have emotional disorders. The groups provide support for families and advocacy for improved services for children and adolescents.

The National Alliance for the Mentally Ill (NAMI)

The National Alliance for the Mentally Ill, a grassroots organization of parents whose primarily adult children have mental illnesses, has established a Child and Adolescent Network (NAMI–CAN) to provide support and information to families who have children and adolescents with biologically based mental illness.

Federation of Families for Children's Mental Health (FFCMH)

A national parent organization has emerged within the past several years, with an exclusive focus on the unique mental health needs of children and youth with emotional, behavioral or mental disorders and their families. The Federation of Families for Children's Mental Health, established in 1989 to mobilize the energies and

talents of families in providing a national voice for children with emotional or behavioral disorders, is rapidly gaining membership and a national following.

Parent Training and Information Centers (PTIs)

Nearly sixty Parent Training and Information Centers exist nationally to provide information and guidance to parents of children with all disabilities (including emotional disorders) about special education services. Public Law (PL) 101-476, the Individuals with Disabilities Education Act (IDEA), provides children with disabilities and their parents specific rights and responsibilities in planning an educational program. The role of a PTI is to assist parents in understanding their unique role in planning and evaluating their child's educational program, and in resolving differences when parents and schools disagree. PACER Center, the publisher of this book, is the PTI which serves Minnesota parents.

The addresses and telephone numbers for all the preceding resources are listed in Appendices C and D of this book.

Family Choices

In general, the thrust of providing mental health and other services to children with serious emotional/behavioral disorders or mental illnesses during the next decade will focus on the importance of normalized settings, such as the child's home, school, and community, over agency or institutional placements, whenever possible. Respect for family choices and priorities is integral to the success of community-based services for children and adolescents.

Though there are still many gaps in services available, there are also many fine programs and services in place and numerous devoted, accomplished and caring professionals who work with children. This book has been prepared for parents who wish to better understand the topic of emotional/behavioral disorders and the types of treatment programs that serve children and youth and have available the kind of information they need to make informed decisions.

NOTESNOTESNOTES

Who Do We Blame? What Good Does It Do?

by Barry Haddle

It seems to be an ingrained part of human nature to look for someone to blame whenever anything goes wrong. This is especially true whenever something goes wrong with a child. Parents blame teachers, teachers blame parents, and they both blame administrators. Even if it were possible to establish blame, what good would it do the child?

The people who suffer most from this blame seeking are the parents of children with emotional and behavior disorders.

Whenever a child has an obvious physical handicap, very few people are insensitive enough to suggest that the parents are at fault. No one says to the parents of a blind child, "If you had raised him properly, he would not be blind." Most people would have more respect for the feelings of the parents of a severely retarded child than to blame the parents for their child's affliction.

We have compassion for these parents and their children. We try to help if we can. The parents of children with mental and emotional handicaps, however, are fair game for all. They must listen to remarks such as: "If he were my child, I'd make him listen!" "The only thing that girl needs is a good spanking!" "He's just lazy, you've got to make him learn!" "What kind of parents would raise a kid like that?" and so on. I'm certain that many more examples could be given by parents who have been victims of such cutting remarks.

Consider the plight of these parents. They often blame themselves. Consumed with guilt, they ask themselves, "What have I done wrong?" In desperation, they seek help from "professionals." They go from agency to agency, all professing to help troubled children. They read book after book written by "experts." They receive counseling and attend seminars. Many spend their savings in a fruitless effort to "find a cure." A few lucky ones do get help, but the success rate is dismally low. For the unlucky majority, the feeling of hopelessness increases as they see little improvement despite all their efforts. Many see a future full of heartache and little hope.

These parents do not need the additional punishment brought on by callous remarks made by others.

The blame-seekers never explain how parents of troubled children can also have "good" children in the same family, nor how some lazy, lawless and otherwise unfit parents can have "good" children. If the parents were always to blame, this would never happen.

Rather than looking for someone to blame, we should all work together to see that the necessary resources are allocated to conduct research and find solutions to these problems. I do not mean that we need more people to invent half-baked theories so that they can write books and conduct lectures. These do nothing more than enrich authors by preying on the desperation of parents willing to try anything.

We need legitimate research by scientists. We need answers about how the mind really works and how it is influenced by body chemistry. Such research, of course, is being done, but not on a scale that bears any relationship to the magnitude of the problem. We need a research program to improve the quality of human life that has the scope of the Manhattan Project.

The whole country would benefit and many presently unhappy parents and children would be eternally grateful.

Who Do We Blame? What Good Does It Do? was reprinted with permission from the *Exceptional Parent* magazine. It appeared in the magazine's December, 1982 issue. No further reproduction is allowed without express permission from the magazine.

The *Exceptional Parent* magazine has served parents and professionals concerned with the care of children with all handicapping conditions (mental, physical, emotional, and learning) since 1971. Yearly subscriptions (eight issues) are available at $18.00 for individuals and $24.00 for organizations, schools, and libraries. To order, write to The Exceptional Parent, P.O. Box 3000, Dept. EP, Denville, NJ 07834-9919, giving your name and address along with the information that you would like a subscription.

Matt's Story (1984)

Written by Matt's Mother

For most of us, the intensity of a painful experience seems to fade gradually with the passage of time. It is part of a healing process that allows us to continue with our lives. But for Matt, the intensity of his pain has remained with him . . . a kind of "hidden heartache" that interferes with his ability to cope and react to life in a normal way. Just to look at Matt, he appears to be like any other six-year-old. He likes Star Wars, Pac Man, riding his Big Wheel, and playing baseball . . . and sometimes he likes to play with other children.

The difference is that although Matt may look like other children, he is not. Matt, who came to us from Korea at six months, was suffering from a serious emotional disorder. When the flight aide placed Matt in my arms, there was an unmistakable difference in the way he reacted. He didn't cry or move but maintained a rigid position and continued a cold, blank stare. I was reassured that sometimes children react this way from a long flight. However, the staring continued, compounded with head banging, poor appetite, and stomach problems.

As time progressed, Matt spent much of his time rocking, banging his head, and exhibiting destructive, overly active and inappropriate behavior. When he was eighteen months, I felt I would no longer accept the many excuses for his behavior from family members, doctors, and other professionals. I was determined that my son would receive the help he so desperately needed.

I thought, "After all, I am Matt's mother. I live with this child all the time, and I know he is not improving. In fact, he is distancing himself further."

And so my search began for help for Matt. Unfortunately, I did not realize at the time that the number of programs, available treatment, or even recognition of emotional disorders in young children is very limited. At the beginning, the treatment centered around sessions with a child psychologist who took an in-depth history of Matt, his behaviors at home and those observed during our visits with the doctor. There was a great deal of discussion concerning parenting skills, and the doctor provided suggestions for working with Matt at home.

Most distressing during this first phase of treatment was the endless number of questions asked me in the sessions. It seemed as if they were probing for some "deep,

dark secret" that would reveal why Matt was responding the way he did to the world around him.

But there *was* no hidden resentment toward Matt. He had come to us with the damage already done within the critical first six months of life. It has taken me a long time to recover from the misplaced guilt that was imposed on me in the beginning.

After six months of treatment, it was determined that more intensive observation of Matt was needed in a hospital setting. I felt so miserable and guilty at the thought of Matt going into the hospital. However, I was exhausted trying to cope with his behaviors all day long. He had to be watched constantly. There was really no other choice. Even routine kinds of activities that most people take for granted such as grocery shopping, visiting friends, and attending church were all but impossible when Matt was along.

Also, it was very difficult to find anyone who was willing to watch him so that I could get out myself. Many times I had to drive fifteen miles to my parents' home to have Matt watched—or they would have to drive to my house—so that I could get some of those errands accomplished.

I envied those parents who didn't have all these problems and felt angry that no one other than my family offered help. Friends and acquaintances would invite my daughter to come to their home, but no one wanted to deal with the "strange little boy."

Matt was hospitalized for one month, during which we were carefully scrutinized concerning our parenting, our own childhood experience and our families. For much of the hospital stay, we were not allowed to visit with Matt unless a staff member was in attendance. Some of the staff were kind and helpful. Others were uncaring and judgmental.

I longed to tell them how I would love to come and judge and comment upon every interaction they had with their own children. I highly doubt they would pass the stringent criteria they had set for us.

During that month I tried to focus my thoughts on one goal: that the doctor could diagnose Matt's problems and begin some course of treatment. At the end of the month, the doctor had indeed observed many of the behaviors that I had described to her so many times during our sessions at her office. She recommended Matt for a new hospital-based program that worked with children who were emotionally disturbed.

Matt made progress during the next two years in this program. He was in a small, safe environment with teacher/therapists to work with him. There was also a therapist who helped parents understand their child's behaviors. Learning effective and new ways to parent Matt and gaining a greater understanding of his delayed development was most helpful.

Again, during this time I was put through intensive analysis. One week the therapist or teachers would praise and encourage me in how I was working with Matt . . . by the next week I was either blamed or criticized for some of the same actions. It was difficult to

cope with the inconsistency of their methods and created needless damage to my own self-esteem.

After leaving the hospital program, Matt was referred for treatment with a child psychologist who has established an excellent relationship with him. We see another doctor in the same group for counseling. The attitudes that these doctors have toward parents is very different from what I had experienced before. They have been very open, honest and consistent in their dealings with us. Their major focus has not been to put needless blame on a family already pushed to an almost unbearable level of stress. Rather, they focus on ways to cope with, understand, and accept Matt's disorder. His problem is internalized. As a family, we can act in ways that will stimulate growth in Matt and help him feel a sense of safety. Nevertheless, to be realistic is to accept that he may never be able to function like other children.

Matt is now in public school, receiving services from special education through an emotional/behavioral disorders program. Within the public school system, I have found there are those persons who care deeply about doing what is appropriate for Matt. There are teachers who care deeply about doing what is appropriate for him. There are teachers and administrators who have taken the time to look carefully at his long history of emotional problems, listened to my observations of Matt and his feelings about school, and implemented suggestions from his doctor. These people feel it is important to work as a team.

Unfortunately, there have been an equal number of school personnel who cannot see past Matt's normal physical appearance and make snap judgements and recommendations that I feel are detrimental to his well-being. These teachers will not accept that a bright child who looks so normal – and who can function normally at times – can have serious emotional problems.

It is their opinion that he is manipulative and spoiled. How I wish he were! I could do something about that.

Matt is consumed with fears that he feels he may be killed. He believes that teachers and other children can change into monsters. He has a distorted perception of what is actually happening, and I worry that he will injure another child or himself while at school.

Being the parent of a child with an emotional disorder has certainly not been easy. At times, I feel so tired and sad and helpless. Now, six years later, I wonder where I found the strength to make it through those early years. Many times I felt as if I was struggling all alone, and I wondered if there was any hope for Matt.

To parents who wonder how they are going to survive living with a child with an emotional disorder, I want to say that there are people who do care about your child and you. Sometimes, you have to be the one to seek out these people.

PACER Center, a parent training and information center, was there for me three and a half years ago at a time when I was questioning whether anyone really cared what happened to Matt. At that time, I was unaware that my child would be entitled to a free, appropriate public education under PL 101-476. I received information from PACER staff and attended workshops on the basic rights and laws and received advocacy and assertiveness training. Since most of PACER's staff are themselves parents of children with disabilities, they have a deep concern and empathy for all parents. I learned that parents can be an important part in developing an appropriate program for their child, and I gained the skills and confidence to become a good advocate for my son.

In the future I would like to see the establishment of support groups for parents of children with EBD. Parents need to feel less alone. Professionals need to consider parents as individuals. We do not all fit into one mold. It does not help to blame parents for their child's problem. It **does** help to enable them to understand, to cope with, and to accept the child, and to teach them ways to help their child.

Professionals work with our children on a limited basis. The children do present frustrations. However, professionals are able to have a break from this frustration. Parents have to cope with the situation on a daily basis.

Parents need to show appreciation to those professionals who put forth an extra effort with their child. Professionals need to feel that we recognize and value these efforts. Parents and professionals need to work as a team.

In the past six years, my life has changed dramatically. My values and priorities are different. I've become a much stronger person. Having Matt has put an enormous amount of stress on our family. Not all family members are able to accept or cope with a child who has an emotional disorder. Some may never be able to overcome their feelings of anger, frustration, and resentment.

That is a part of reality that I have come to accept.

Matt's future is uncertain at this time. He makes progress and also experiences regression. During these years, I have had to give a lot of myself; it has been worth it. But I have also learned it is important to do something for myself, too.

Matt's Story – An Update

The preceding story was written in 1984, when Matt was six and one-half years old. His mother provided the following update on his progress in 1990.

Matt is now almost fourteen years old and in the eighth grade. The little boy who was once so dependent on us has grown into an adolescent preparing to face the world in his "own way." His "own way" is different from that of other adolescents. He can be aggressive and hostile and yet there is a very vulnerable side to Matt, too. The issues that faced our family with a child with an emotional disorder have been replaced by new and different concerns with an adolescent. The little boy who lashed out in anger is now taller and stronger than I am and new techniques must be used to manage behavior.

We have all rejoiced in the successes he has experienced along the way – swimming on a varsity swim team at our local high school and an award for academics and attitude for one quarter during his first year in junior high. These are the memories we cling to when we are forced to face the fact that our son's emotional disorder is not going to go away.

Matt still views life differently than others. He has difficulty controlling his impulses, steals from stores and other people and has low self-esteem. Medication, which was ineffective at a younger age, is now helping him to cope with his daily routine. Individual therapy has been replaced with group therapy for adolescent boys. This has been a safe and reassuring place for him to go – a place where he feels accepted and understood by others. Matt is also becoming an important member at the IEP meeting. He is learning to advocate for his own needs and to feel that he is able to determine goals for his own life.

Finding support and reaching out to other parents whose children and adolescents have emotional disorders has been a very important part of my life. Like Matt, I needed the kind of support and sharing that comes from being with others who understand the difficulties in managing an adolescent with emotional disorders. Attending a support group offers me the chance to talk freely with people who are caring and nonjudgmental.

Throughout the past fourteen years, professionals have frequently entered and exited our lives. Some were sure they had the answers. What I have found is that Matt's abilities fall somewhere in the middle of all those varying opinions. What the future holds for Matt remains uncertain. However, I recognize the need for good transition planning and support for independent living skills. Matt deserves a chance for a life that is fulfilling for him. I recognize that this transition will be handled in his "own way" too.

NOTESNOTESNOTES

Recommended Reading

Before beginning to address frequently asked questions about emotional or behavioral disorders, several extremely helpful books about such disorders and families deserve mention. Parents who wish to seek more information in addition to that found in this guidebook will find the books that are listed below to be helpful resources.

Help For Your Child, A Parents' Guide to Mental Health Services. **(1978). Sharon Brehm. Englewood Cliffs, NJ: Prentice-Hall, Inc.**

The author, a psychologist, has sought to assist parents to make the best possible use of their own expertise and to enable them to ask sensible questions. She sees parents working as partners with professionals in the helping process for their child – once they have the knowledge needed to understand what's happening and to be able to evaluate the program(s) offered to their child.

The Caring Family. **(1982). Kayla F. Bernheim, Richard Lewine, and Caroline T. Beale. New York: Random House.**

This book deals with understanding what happens to a family with a member who is emotionally troubled. The authors deal with the guilt feelings so many parents suffer, and the stress undergone by the family when trying to keep life on an even keel.

Taking Charge: A Handbook for Parents Whose Children Have Emotional Handicaps. **(1988). Katharin Kelker. Portland, OR: Portland State University, Regional Research Institute for Human Services, Families as Allies Project.**

This parent handbook offers a compendium of information, from the feelings experienced by parents on discovering their child has a serious emotional disorder, to specific information about the different disciplines and specialists, and the types of services available to children and families.

Focal Point. **Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.**

Focal Point is the newsletter of the Regional Research Institute's Families As Allies Project. Published several times per year, this informative bulletin provides parents and advocates with updates on state and national policies and issues and initiatives relevant to families of children with serious emotional disorders. A subscription to *Focal Point* is free and available by contacting the Regional Research Institute for Human Services, Portland State University, P.O. Box 751, Portland, OR, 97202-0751.

***Update*. Tampa, FL: Florida Mental Health Institute, Research and Training Center for Children's Mental Health.**

For parents who are interested in children's mental health research, a bulletin called *Update* is available through the Research and Training Center for Children's Mental Health, Florida Mental Health Institute, 13301 Bruce B. Downs Boulevard, Tampa, FL 33612-3899.

How Do I Know If My Child Might Have an Emotional or Behavioral Disorder?

Among all the dilemmas facing the parent of a child with an emotional problem, the first question—whether a child's behavior is sufficiently different to warrant a comprehensive evaluation by professionals—may be the most troublesome of all.

Certainly, no one wishes to begin the process of seeking help for his or her child, of having the youngster labeled emotionally disturbed unless there is "really" a problem.

Determining whether there is "really" a problem can, of course, be very tricky. Normal changes in a child's behavior due to growth and development make it difficult to discriminate between behavior that's shown by a child going through a bad, but temporary stage that he or she will grow out of . . . and one that deserves professional attention. Children who have frequent, severe temper outbursts or who may destroy toys may appear "troubled" to some parents, while others perceive the same behavior as "asserting independence" or "showing leadership skills."

More than one mental health practitioner has commented that the question may be easier to handle by parents who have raised other children; the veteran parent has other youngsters around to serve as comparisons. He or she can contemplate, "Is Tom's behavior now the same way Andy acted when he was going through the 'terrible twos' and can we expect him to outgrow it also?" Or, "Is Sally going through the same thing Karen did when she was fifteen . . . or is this something more serious?"

While there is no substitute for the common sense of parental knowledge, certain guidelines are also available to help parents make this kind of decision. In *Help for Your Child, A Parent's Guide to Mental Health Services,* Sharon Brehm suggests three criteria to use in judging whether a child's behavior is "just normal" or a sign that the child needs help:

1. The **Duration** of a Troublesome Behavior—Does it just go on and on with no sign that the child is going to outgrow it and progress to a new stage?

2. The **Intensity** of a Behavior—For instance, while temper tantrums are normal in almost all children, some tantrums could be so extreme that they have a very frightening aspect and suggest that some investigation would be wise.

Parents should pay particular attention to behaviors such as feelings of despair or hopelessness; lack of interest in family, friends, school or other activities once

considered enjoyable; or behaviors which are dangerous to the child or to others. Attempts at self-injury or threats of suicide, violent behaviors, or severe withdrawal that creates an inability to carry on normal routines must be regarded as emergencies for which parents should seek immediate attention, through a mental health or medical clinic, county mental health hotline, or crisis center.

3. The **Age** of the Child – While some behavior might be quite normal for a child of two, a parent's observation of other children of their own youngster's age may lead to the conclusion that the behavior in question isn't quite "right" for their child, age five. Not all children reach the same emotional milestones at the same age, but extreme deviations from age-appropriate behaviors may well be cause for concern.

Parents will also want to consider whether their child's behavior could be caused by other factors:

- Whether a specific physical condition (allergies, hearing, etc.) could be affecting the behavior.
- Whether school problems (peer relationships, learning problems) are creating stress for the child.
- Whether changes in the family (divorce, new child, death) have occurred which may be causing concern for the child.

Young Children

Special consideration needs to be given to identifying behaviors of concern in very young children. Their well-being is so connected with that of the family that services must be developed with and directed to the family as a unit. Most often, the first indications that an infant may be experiencing significant problems will be delays in normal development. An infant who is unresponsive to his or her environment (doesn't show emotion such as pleasure or fear that is developmentally appropriate, doesn't look at or reach for objects within reach or respond to environmental changes such as sound or light), who is over-responsive (easily startled, cries), or who shows weight loss or inadequate weight gain that is not explainable by a physical problem (failure to thrive), should have a thorough evaluation. Parents who have questions about their child's development should call their pediatrician or family physician. Many doctors who include young children in their practice will have materials available for parents on normal childhood development.

Toddlers may have a tremendous range of behaviors that would be considered developmentally appropriate, depending on the child's own history. However, any significant delays (six months or more) in language development, motor skills or cognitive development should be brought to the attention of the child's pediatrician. Children who become engrossed in self-stimulating behavior to the exclusion of normal activities or who are self-abusive (head banging, biting, hitting), who do not form

affectionate relationships with care providers such as baby-sitters or relatives, or who repeatedly hit, bite, kick or attempt to injure others should be seen by their pediatrician or family physician and, if indicated, by a competent mental health professional.

Especially with a first child, parents may feel uneasy, uncomfortable, or even foolish about seeking an evaluation for a very young child. While sorting out problems from developmental stages can be quite tricky with infants and toddlers, early identification and intervention can significantly reduce the effects of abnormal psychosocial development. Careful observation of infants and toddlers as they interact with caregivers, parents, or their environment is one of the most useful tools that parents or physicians have, since many mental health problems cannot be diagnosed in any other way.

Part B of the Individuals with Disabilities Education Act (IDEA, PL 101-476) provides services for children from age three through five who have disabilities and, under Part H (formerly part of PL 99-457), establishes a new early intervention state grant program to serve infants and toddlers from birth through the age of two.

This law specifies that states who apply for and receive funds under Part H must provide a multidisciplinary assessment of infants or toddlers who are experiencing significant delays in normal development, and identify services appropriate to meet any identified needs in a written Individualized Family Service Plan (IFSP). Parents who have questions related to preschool or early intervention programs should call their local school district offices or their state's Department of Health or Human Services for guidance.

Once parents have decided that their child or adolescent has behaviors that deserve at least a look by a mental health professional, the question then becomes where to turn for an evaluation.

If the child is of school age, a first step could be to approach the school's special education director and request an assessment by the school psychologist or teacher.

Should that not provide satisfactory answers to parent concerns or if the family doesn't want to involve the school at this point, there are several other places to turn for an evaluation.

A family doctor can rule out physical health issues and refer families to an appropriate child or adolescent psychologist or psychiatrist. Also, many hospitals and increasing numbers of community mental health centers offer comprehensive diagnostic and evaluation programs.

Parents looking for evaluations or services through private physicians, hospitals and other practitioners should have ample private resources, have good insurance coverage, or be eligible for Medical Assistance (Medicaid).

For Medicaid-eligible children, the Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) provides preventive health care, including screening (assessment), diagnosis, and appropriate mental health services for children.

An EPSDT **screening** is a comprehensive health evaluation, including the status of a child's emotional health. A child is entitled to periodic screenings, or an "interperiodic" screening whenever a physical or emotional problem is suspected – and is entitled to receive services to address such problems from any provider (public or private) who is a Medicaid provider. Federal law explicitly states that any medical services needed by a child to address problems diagnosed in the screening process be provided, whether or not those services are covered under the state plan. States cannot limit the number of doctor visits or hospital days for treatment that is medically necessary for a child under the EPSDT program.

Other parents, particularly those in rural areas, may want to first approach their county's public health nurse or mental health services director. Either may be able to direct them to an evaluation program available in their area.

Community mental health centers are also a good source of help, and can be less expensive than seeking out a private doctor or mental health professional. Parents will want to ask for professional staff with experience in evaluating the mental health needs of children.

Cultural Considerations

Appropriate assessment of a child's mental or emotional status is key to developing appropriate school or mental health services. For children who are cultural or racial minorities, parents will want to know how, or if, those differences will affect assessment results.

Tests, by their very nature, have been developed to discriminate. If everyone taking a test scored the same, then the test would be of no use. What's important, though, is that tests discriminate only in those areas they were designed to measure – such as depression, anxiety, etc. – and not along measures such as cultural background, race, or value systems.

If the professional who is responsible for assessment is not of the same cultural background as the child, parents may want to ask what his or her experiences have been in cross-cultural assessment or treatment. Professionals who are sensitive to issues of bias related to language, socioeconomic status or culture in formal assessment tools should willingly share such information with parents.

One way of minimizing the effects of cultural bias in obtaining an appropriate diagnosis is to utilize a multidisciplinary approach to assessment – involving persons from different backgrounds (teacher, therapist, parent, social worker) in completing the assessment. Do the various professionals agree? Did the professionals use family

information about the child's functioning at home and in the community to aid in making a diagnosis? Does the family believe the assessment is accurate?

When a multidisciplinary approach is not practical or available, the person providing the assessment should give a battery of tests to reduce the effects of bias that might exist in an individual test when making a diagnosis or determination that a child is in need of mental health services.

If children from similar ethnic or cultural groups appear to be overrepresented in the program that has been selected or recommended for a child, parents should carefully examine the procedures for determining their child's placement.

If parents decide that the placement decision was not influenced by racial or cultural bias, that information can increase confidence in the therapeutic program selected for their child.

NOTESNOTESNOTES

What Is an Emotional or Behavioral Disorder?

Although childhood is generally regarded as a carefree time of life, as many as fourteen percent of children and adolescents experience emotional difficulties growing up. The process of identifying an emotional disorder is a difficult one for many reasons. For instance, it cannot be stated with certainty that something "goes wrong" in the brain, causing a child to act in a particular way. And, contrary to early psychiatric theories, it is impossible to conclude that a mother or father did something "wrong" early in the child's life, causing an emotional or behavioral disorder or mental illness.

Experts continue to disagree on whether emotional disorders have a genetic component or whether they are "caused" externally or internally. Promising research in the field of nuclear medicine has shown that the actual brain function—the way information is received and processed—is different for children with some types of emotional disorders than for children who do not have those problems.

While some professionals and parents may tend to latch onto simple explanations of why a child has an emotional problem, causation is complex, and often the result of multiple factors interacting. It is perhaps more useful for an individual family to concentrate, not on the "cause" of an emotional disorder (except to the extent that cause can be readily agreed on), but on their role in helping their child to learn the adaptive skills and appropriate behaviors he or she lacks. The child judged to be disturbed or troubled is probably not going to do anything that other children do not. It's simply that inappropriate behavior will be seen more often, or she or he will misbehave in more extreme ways. Parents are in a good position to judge when their child's behavior has gone beyond the realm of what all children do at one time or another and into a more extreme phase.

Sometimes it is difficult for parents to seek an emotional assessment for their child, even when they perceive it may be needed. The realization that a child's behavior may not be appropriate is often painful, and personalized as a failure of the parent. Many parents are afraid their child may be inappropriately labeled, and the array of diagnoses, medicines and therapies have not been agreed upon by all specialists in the field. Still others are turned off after obtaining an assessment for their child only to discover that the evaluator believed that emotional disturbances originate in family dynamics, and that "parenting skills" classes were the best way to address the child's problems.

Different professionals view emotional or behavioral disorders in different ways. Their outlook—and their treatment plan—is usually shaped by their training and their philosophy about the origins of emotional/behavioral disorders.

Though the philosophical orientation or direction may not seem important to parents who are frantically seeking a way to get their child to stop terrorizing or being terrorized by other neighborhood children, it's still recommended that parents discuss such beliefs with the professional they contact. Since the treatment program for the child will stem from the professional's philosophy, parents should be sure they agree with "where the professional's coming from." Otherwise, their cooperation in the treatment process may be limited and hurt its chances of success. When seeking a treatment program for their child, parents may also want to seek a second opinion if they disagree with the approach suggested by the first mental health professional.

Examples of Emotional/Behavioral Disorders and Related Conditions

A diagnosis of an emotional or behavioral disorder made by a psychiatrist will be based on one of several classification systems commonly used in the United States. The most well-known diagnostic classification system is the *Diagnostic and Statistical Manual of Mental Disorders* (3rd edition, Revised), or *DSM-III(R)*. A second system, the *International Classification of Diseases Manual (ICD)*, is used in the U.S. less often. The following are examples of diagnoses from *DSM-III(R)*:

Adjustment Disorders describe behaviors children may exhibit when they are unable, for a time, to appropriately adapt to stressful events or changes in their lives. Children with adjustment disorders may have difficulty in educational or social domains, or they may have aggravated physical symptoms that do not have a medical basis.

Affective Disorders (Mood Disorders) refer to disturbances of affect or mood, which are not due to physical or mental illness. Bi-Polar Disorder (sometimes called manic depressive illness) and Childhood Depression (also known as Major Depressive Episode) are examples of affective disorders. Affective disorders are cyclical in nature, meaning that children have periods of normal feelings and behaviors between episodes of depression or manic-depression; such disorders generally respond to medications, especially when combined with counseling or psychotherapy.

Symptoms of Bi-Polar Disorder (Manic Depression) include an alternating pattern of emotional highs and emotional lows or depressions. Depressive symptoms are prominent and last for a full day or more. Childhood Depression (Major Depressive Disorder or Episode) is often characterized by a change in physical demeanor – either a noticeable slowing down or "speeding up" (agitation), loss of interest in activities usually enjoyed, inappropriate feelings of guilt,

or suicidal behavior. In children, aggressive or hostile behaviors may mask an underlying depression.

Anxiety Disorders are a family of disorders (school phobia, post-traumatic stress disorder, avoidant disorder, etc), where the predominant feature is exaggerated anxiety. Anxiety disorders may be manifest as physical symptoms, such as headaches or stomach aches, as disorders in conduct (work refusal, etc.) or as inappropriate emotional responses, such as giggling or crying.

Disruptive Behavior Disorders encompass some of the more common disorders of childhood, including Attention Deficit Hyperactivity Disorder (ADHD) and Conduct Disorders.

ADHD, defined as a pattern of behavior combining inattention, impulsivity, and hyperactivity, is usually present in a child before the age of seven. These children may "lose" or misplace schoolwork or do poorly in school due to distractability or inattentiveness. Some children with attention deficit hyperactivity disorder have secondary diagnoses, such as learning disabilities, conduct disorders, or depression.

Conduct Disorders as a category refers to youth whose behaviors violate social norms. Some children with conduct disorders may refuse to follow rules at home or in school, become truant, delinquent, or even violent. An appropriate, supportive behavioral intervention program is a key component of a treatment program for such youth.

Thought Disorders (Psychoses) are impairments of thinking or mood in which a child's interpretation of reality is severely abnormal.

Schizophrenia is a serious emotional disorder characterized by loss of contact with environment and personality changes. Hallucinations and delusions often exist as symptoms of this disorder, which is frequently manifest in young adulthood, although the symptoms may also occur at a younger age.

Pervasive Developmental Disorder (PDD) refers to a disorder where the brain has difficulty processing information; characteristics of pervasive developmental disorder may include hallucinations, delusions, or a faulty perception of reality. PDD is a disorder of thought rather than one of mood.

School professionals do not generally use diagnostic classification systems in deciding whether a child has an emotional or behavioral disorder. While they must consider a child's mental health diagnosis when evaluating needs, they also rely on a set of criteria provided by their state Department of Education, based on the requirements contained

in PL 101-476 (formerly PL 94-142). Many children with psychiatric diagnoses have problems that are not severe enough to warrant special education intervention. Or, they may receive special education services in other areas, such as reading or math. Still others have needs that significantly interfere with their ability to learn the necessary academic, social or behavior skills to be successful in school, and which require special education services in emotional and behavioral areas.

The school's responsibility is to provide services for students with emotional or behavioral disorders when their problems are so severe that they cannot succeed without special education intervention. Many children served by schools may not have an outside mental health diagnosis; rather, their emotional and behavioral needs **in school** determine their eligibility for special education.

Seriously emotionally disturbed is defined under PL 101-476 as a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects educational performance:

- An inability to learn that cannot be explained by intellectual, sensory, or health factors.
- An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
- Inappropriate types of behavior or feelings under normal circumstances.
- A general pervasive mood of unhappiness or depression.
- A tendency to develop physical symptoms or fears associated with personal or school problems.

Children with diagnoses from psychiatrists, psychologists or neurologists may receive special education services under the label of SED if they qualify under the federal definition, or under the definition established by their state's Department of Education. Schools do not look at precise medical labels exclusively when making a determination of whether a child needs special education services, but evaluate the educational needs of children as they are affected by emotional and behavioral disorders.

What Kinds of Programs Should I Be Looking for or Considering?

> ***"Daddy, when am I coming home?"***
>
> . . . .An eight-year-old boy in a facility 150 miles from home, whose parents were unable to secure support services from their own county human services agency (1990 Minnesota Report to the Governor and Legislature).

For many years children have been placed in unnecessarily restrictive settings to receive mental health services, because community-based models for such services did not exist. Although some children do require residential programs to address serious emotional disorders, many others could be appropriately served in their own homes if services were available. Although states and communities have embraced the concept of providing mental health services to children in the context of their families, funding patterns are slower to change.

The Child and Adolescent Service System Program (CASSP) of the National Institute of Mental Health has provided states with a model for community-based, coordinated services for children with serious emotional disorders. Components of a full "System of Care" as conceptualized by CASSP are listed in Appendix E of this book. The philosophy behind such a model is one of respect for the child and his or her family – and on their right to receive services in their own community, in the same way as services are provided for other chronic health problems.

A general listing of the kinds of mental health services that a community might provide for children and their families follows. While few communities have all such services in place, it may be helpful for parents who do not know "what to ask for" to have an idea of the possibilities. It is important that parents begin to request the kinds of services needed for their child and family; services that may be needed usually do not exist without demand.

Outpatient Treatment

One of the most commonly used and therefore most readily available interventions is individual, group, or family therapy. This service may be provided by community mental health clinics, child guidance centers, private outpatient clinics, or through private mental health practices. Outpatient mental health care practitioners include psychiatrists, psychologists, clinical social workers, psychiatric nurses, and mental

health counselors. Outpatient counseling or therapy may be provided daily, weekly or monthly, depending on need, and is often used in conjunction with other treatments (medication, school program, etc.). Examples of outpatient treatment would be individual or group therapy, parent training on behavioral interventions, or medication management.

Home-based Intervention Services

Local or county mental health centers can help parents and families access home-based services, where available. The purpose of home-based services is to prevent the need for out-of-home placements for children in crisis. They represent a significant departure from traditional mental health services in several respects. Home-based services tend to be of brief duration (from several weeks to several months), and are provided to children and families in their homes.

Most successful home-based programs offer 24-hour crisis services. Therapists, who generally work in teams, provide in-home crisis intervention to prevent out-of-home placement for the child with an emotional disorder. They assess child and family needs and provide training in behavior management techniques and problem-solving skills. The team may also assist the family with home management skills or help them locate other necessary resources, such as medical or legal services.

Home-based intervention services are not designed to eliminate the need for other types of mental health services, including residential care. However, their use will help to ensure that those children who are referred for residential treatment will have had the opportunity to try less restrictive alternatives.

Educational Services

Public schools must provide special education services for children in Minnesota ages birth through twenty-one with serious emotional or behavioral disorders who meet federal and district criteria. A psychiatric label from a mental health professional will not necessarily mean that a child is in need of special education. For specific information related to services provided through special education programs, please turn to the chapter in this book entitled "What Help Can I Expect from the School District for My Child with an Emotional or Behavioral Disorder?"

Day Treatment

Day treatment programs for children with serious emotional disorders (sometimes called partial hospitalization programs when day treatment is provided in a hospital setting), provide an integrated set of educational and mental health services. Day treatment is often used as a follow-up to residential placement, but it may also provide a community alternative to residential placement when a child has not been successful in a less restrictive setting. Day treatment programs include academic instruction, as

well as individual and group counseling. Many programs have a strong family participation component; some require that parents participate in family therapy. For adolescents, day treatment services should also include vocational training and work or supported work experiences, if needed.

Traditionally, day treatment programs for children and adolescents have been provided in community mental health or hospital settings. More recent programs have focused on bringing the needed mental health services into school environments, a move which not only facilitates re-entry into regular school programming, but which provides more opportunity for normalized educational activities for the children capable of participating.

Parents who are considering day treatment for their child should ask about the philosophy and program rules before making a decision. While most day treatment programs focus on the needs of the children in their charge, some assume that the child's problems originate in "family dynamics" and will discharge a child from the program if the parent refuses to participate in family therapy or misses too many sessions. Such policies should be questioned if not appropriate to the needs of the child.

Residential Programs

Historically, residential programs were available as acute psychiatric inpatient care in psychiatric hospitals, psychiatric units in regular hospitals, or placement in a regional treatment center or state hospital for long-term care. These programs still exist, and are generally reserved for children whose functioning in their own homes and relationships with other family members have become impossible due to an emotional disorder.

Community-based residential programs such as group homes may be offered for a child whose therapy needs are less intense than those provided in medical settings, but who still requires a fully-structured living environment. Group homes may provide educational services on-site; more often, the child or adolescent will be transported to a public school program for a portion of the day.

Children may be recommended for out-of-home placement for a variety of reasons, including assessment and diagnosis, crisis intervention, psychiatric treatment, abuse prevention, or education. Parents should have a clear idea of the type of program their child may be entering, the treatment philosophy and goals of the recommended placement, the anticipated or average length of stay, what costs, if any, the family will be expected to assume, and what the criteria for the child's return to the family home will be.

An out-of-home placement is not a quick-fix for a child or adolescent who's experiencing an emotional crisis. Generally, such placements occur only after other, less restrictive interventions have been tried, and have not been successful.

Foster Care

Another arrangement for service might be provided through foster care. Parents who are unable to handle the extreme behaviors of their child in their own home can seek, through their county or state human or social services department, to place the child in a foster home. At times, especially when other children in the family home are at risk, placement in an alternative home can give both the child and the family a needed break. In this arrangement, the child could receive professional help for his or her emotional or behavioral problem and still remain in a home setting and attend a community school or day treatment program. Foster care providers who care for children with serious emotional or behavioral problems should have specific training in behavioral intervention and crisis management techniques; in some states homes where foster parents have received such training are called **therapeutic** or **treatment** foster homes.

Placement in a foster home cannot take place unless social or human services believes there is a documented and genuine need for the child to leave his parental home. Also, before a child is placed in foster care, appropriate family-based interventions should have been attempted to enable the child to remain at home.

Shelter Care

Shelter care is a residential service available in many communities to meet temporary out-of-home placement needs of children and adolescents. A shelter care facility may be placement with an individual family or in a group home; **shelter care** provides temporary care to children who cannot remain at home due to a crisis. Educational services must be provided to the child or adolescent in a shelter care placement.

Crisis Nursery

A crisis nursery accepts children, generally from birth to age five, for very short-term placement, usually no longer than several days. Parents who are too stressed to have their children at home may use a crisis nursery to prevent the possibility of neglect or abuse. Because **crisis nursery** care is among the newer family support services, it may not be routinely available.

Two other services that parents will want to know if their state provides for children with serious emotional disorders are **case management** *and* **respite care.**

Case Management

While not a mental health service per se, case management has been described as "perhaps the most essential unifying factor in service delivery" (Behar, 1985). Good case management involves locating and accessing services for individual children, advocacy on their behalf with the multiple systems that offer services, overseeing the

development and implementation of an adequate treatment plan, reviewing their progress, and coordinating services across agencies.

Respite Care

Respite care would also not be classified as a mental health service in that it is not directly therapeutic to the child. However, respite care – defined as the provision of temporary care to the child for the purpose of offering relief to the caregivers of a child – is the service that most families say they need in order to keep their child at home. Many parents report that they are unable to leave their child who is troubled with a sitter or relatives, that day care centers will not accept the child, and that it is not safe for him or her to be home alone. Caring for a child with serious behavioral concerns is a highly stressful activity. Having occasional periods of respite can significantly reduce stress in the family, and enhance the family's ability to maintain the child in the family home.

Respite care can take many forms. Care may be provided in the family home, allowing parents to get away for a few hours, or may take place in the respite provider's home. In some cases, group homes or other residential facilities may provide overnight or weekend care. While most states have respite care available to parents of children with physical or developmental disabilities, it has not routinely been offered or available to parents whose children have emotional problems. If such providers can be made available as respite providers for children with emotional disorders, care should be taken to ensure they have appropriate training to handle the emotional, social, and behavioral needs of an individual child.

NOTESNOTESNOTES

What Types of Professionals Work with Children Who Have Emotional or Behavioral Disorders?

PERSONNEL

Depending on the nature and severity of a child's problems, there is an array of professionals who provide mental health services to children and adolescents. Included here are a representative sampling of such professionals and their areas of expertise.

Psychiatrist

A psychiatrist has completed four years of medical school as well as four additional years of specialized training in psychiatry – the study, diagnosis and treatment of mental illness. Those who specialize in children and adolescents must complete two additional years of training with children. Since they are licensed physicians, psychiatrists are able to prescribe medications which may be used to treat specific disorders. They also provide therapy and, where necessary, request related medical testing such as brain scans, endocrine testing, blood analysis, etc., in cases where a medical or biochemical link is suspected.

Psychologist

A psychologist does not have a medical degree and cannot prescribe medication. However, both a "licensed consulting psychologist" and a "licensed psychologist," professional titles accepted in many states, have completed advanced studies in human behavior and are qualified to evaluate (assess) a child and conduct therapy programs.

To become a **licensed consulting psychologist** a person must complete a Ph.D. program in psychology, have at least two years of post doctoral experience in the field of psychology and pass both written and oral tests.

To become a **licensed psychologist** a person must have a master's degree in psychology, have at least two years of experience in the field and pass a written test required by the licensing board.

A **school psychologist** has studied behavior and mental processes and has been trained to work with behavioral concerns in the schools. School psychologists also administer and interpret various academic, behavioral and aptitude tests. Most states require specific licensure for school psychologists.

Psychiatric or Clinical Social Workers

These professionals have received training as therapists and work with individuals or families. Both psychiatric and clinical social workers have received advanced training in providing therapeutic interventions to individuals and families under stress; psychiatric social workers specialize in working with persons with emotional disorders and their families. **School social workers** may conduct counseling sessions with children, or coordinate efforts that bring together the child, family, school, and other important persons in his or her life.

Psychiatric Nurses

Psychiatric nurses are registered nurses (RNs) who have taken further studies in the field of psychiatry. They often work closely with a psychiatrist, supplementing the services he or she is able to offer directly.

Special Education Teachers

Special education teachers who work with children experiencing emotional or behavior disorders have specific training in developing structured and supportive behavior plans. Their special role will be described in the section on "What Help Can I Expect from the School District for My Child with an Emotional or Behavioral Disorder?"

Psychometrician

A psychometrician is an individual with specific training in coordinating and scoring testing of children/adolescents in a number of standard psychological tests.

There are many other types of professionals who staff mental health treatment programs and they go by many assorted titles. Rather than trying to list and define them all here, parents are advised – at the first meeting at a facility they've contacted – to discuss the backgrounds of the staff members and find out more about the individual qualifications of the people who will be working with their child. It will be the parents who make the final judgement as to whether they think the staff has the qualifications to offer a helpful program to their child.

A word of caution, however. While it may be tempting to judge most favorably those programs or individuals with the most academic degrees hanging on the walls, one director of a large residential treatment center says he does not hire on the basis of degrees alone, but looks for people with compassion, empathy and proven experience in working with children and adolescents . . . and his center has produced some fine results with children for whom hospital-based programs were not helpful.

MEDICATION ISSUES

Another important question to be considered when deciding on a program for the child involves the use of medication as part of his or her therapy plan. Psychopharmacology (drug therapy) is a rapidly expanding method of treatment for some children or adolescents with emotional disorders. While not a panacea for the treatment of any disorder, medication as part of the treatment process shows promising results for some children.

Any unusual behaviors exhibited by a child which occurred after medication was begun as part of a therapy plan should be reported to the professional who prescribed the drug. Parents who have concerns about their child's response to medication are entitled to have their questions answered fully. Questions to consider are:

- What are the potential side effects of the medication recommended?
- How will the optimal dose be determined?
- Are there alternative medications which can be tried if the one recommended does not work or has severe side effects?
- How frequently will the medication's use and effectiveness be monitored and by whom?

Some professionals recommend keeping the use of medication at a minimum, believing that the long-term answer to their patient's problem lies in changing behaviors and attitudes and self-images through talk or play therapy, or behavior management. However, many parents as well as professionals will attest to a need for medication as part of a child's therapy plan. Childhood depression is one example of a disorder where medication is considered the preferred therapeutic intervention.

Parents who believe that medication should be at least considered for their child will need to find a program that is connected to a psychiatrist or one that works closely with a pediatrician. The parent who has strong beliefs—either for or against the use of medication—should discuss the issue thoroughly with the child's case manager or primary service provider before their child begins a program.

NOTESNOTESNOTES

What Are Some of the Different Philosophies and Therapies?

The following list is by no means comprehensive, but is provided to give parents and families brief descriptions of various approaches to the treatment of emotional disorders.

Psychotherapy

Psychotherapy, a broad term, includes those kinds of treatment where the goal is actually to change a child's personality – rather than simply his or her outward behavior.

This might be done through **psychoanalysis**, a course of treatment where the child is assisted on an individual basis. In psychoanalysis, the therapist attempts to bring an unconscious conflict to the patient's awareness and then help him or her deal with the conflict.

A psychodynamic approach to a child's problems is geared to changing the way children think or feel about themselves to ultimately change their behavior. Treatment would rely on **talk** therapy (individual talk sessions with a therapist) or **play** therapy (particularly when children are very young or have limited verbal skills).

A second type of psychotherapy, **interpersonal therapy** is based on a belief that problems arise from difficulties the individual has relating to other people. It helps children through individual counseling combined with group sessions to understand their present relationships and how to establish new and satisfactory ones.

A third type, **client-centered therapy**, holds that people have problems because they're not able to be their true selves, that they act unnaturally or in conflict with their internal wishes because of external pressure. This kind of therapy tries to help the child become his or her own person.

Behavior Therapy

Rather than focusing on a problem's origin and seeking to change personality, **behavior therapy** concentrates on a child's outward behavior and seeks to change those aspects of it that are inappropriate or produce negative results. Typically, behavior therapy programs are designed to take less time than are those seeking to produce underlying personality changes.

In the behavioral approach, problems are thought to occur because children have been previously rewarded for their problem behavior (for instance, a child might receive the

attention he wants only when he behaves inappropriately). Therapy based on this philosophy involves changing the pattern of rewards and punishments children receive from their surroundings so that their behavior will change. Behaviorists do not focus on finding internal "causes" of emotional or behavioral problems; rather their emphasis is on bringing about positive changes in a child's behavior. Parents would be closely involved in implementing a total behavioral program for their child.

Cognitive Therapy and Social Skills Therapy

Cognitive therapy introduces problem-solving skills and self-instructional strategies to a child (either in groups or individually) in an effort to modify behavioral and emotional responses.

Many children with emotional or behavioral problems lack basic social "know how," with both peers and with adults. **Social skills** therapy or training helps children to interpret cues in their environment (body language, verbal interactions) so that they can interact more effectively and appropriately.

Ecological Treatment

An **ecological approach** to treatment reflects a belief that helping children goes beyond the perspectives just described. This philosophy sees children as part of a larger community (that is, their family, their class at school, their neighborhood friends) that must be understood and often restructured to encourage their growth. Treatment involves working with all the important people in the group where the problem occurs (not just with the parents) and perhaps modifying the environments or stimuli that are a problem to the child. The focus is on what's happening in one of those social systems at the present time, not on what might have happened in the past, and on dealing with present difficulties. Family therapy, which assumes that families can bring about positive changes in behavior, is an ecological treatment model.

Medical Model

Children being treated under a **medical (biological) model** philosophy would have been diagnosed as having a specific "illness" or a symptom pattern that might be alleviated by appropriate medication. A treatment program would involve medical practitioners such as a psychiatrist, who has a medical degree, a pediatric neurologist or a pediatrician.

Parents should also be aware that programs in this category may be the most likely to be eligible for insurance coverage and Medicaid (MA) because they relate to a diagnosis by a psychiatrist or neurologist and are conducted or supervised by medical

personnel and, often, may be connected to hospitals. Less likely to be eligible for coverage are programs conducted by "nonmedical" personnel.

Treatments based on the medical model may involve the use of medications, or drug therapies, with a child. The focus of the treatment would be on the child's "illness" and less on the family structure and pattern of behavior as a possible cause of the problem.

Even children diagnosed under a medical model may respond to appropriate behavioral interventions as part of a total therapeutic program, and families may play a role in restructuring the child's inappropriate behaviors by learning new behavior management techniques. **Parent effectiveness** counseling may provide techniques to parents to improve their relationship and dealings with a child who is disturbed, regardless of the model under which a child is diagnosed.

Therapy programs for children can take several forms. For instance, a child might meet individually with his or her therapist for talk sessions. Or young children might engage in play therapy, where it's hoped they will reveal feelings and conflicts through play situations. A family might be asked to meet with the therapist as a unit so that problems with family relationships can be worked through. Children may have written, supportive behavior plans that reward, and thereby increase, positive behaviors. Finally, a child might meet in a group with other children who are experiencing similar emotional or behavioral problems.

In the examples of therapeutic approaches just described teams of physicians, psychologists, social workers, educators and parents may be involved and working in cooperation.

It should be noted that many of the approaches may be, and frequently are, used in combination. For example, a child who is taking medication can also benefit from other forms of therapy at the same time. Moreover, the more recent and most effective approaches in treatment are family-based; that is the family is included in determining the approach, the options, and in effecting the actual strategies to improve their child's functioning. Services which support and strengthen the families of children with serious emotional or behavioral disorders (such as respite care) are not traditional therapies but are a critical part of a total mental health program for many children who might otherwise be placed in more restrictive settings.

Parent Support

There may be parents who after consideration conclude that their family functions well as a unit. They may feel that the manner in which they relate to their children has not led to problems for their child with an emotional disorder or his or her siblings, and, therefore, that the root of the child's problems rests with a cause – possibly unknown – other than his or her family relationships. Other parents may believe that events in a child's life were important in the development of an emotional or behavioral

disorder; still others may perceive that they are responsible for the onset of their child's emotional or behavioral problems.

Regardless of personal experiences or beliefs concerning their child's emotional or behavioral disorder, many parents find that sharing information about their child with other parents is affirming and helpful. Such parents may wish to seek out a self-help or support group. This kind of group seeks simply to help parents and families to cope with their child and keep stress at a minimum. The focus of support groups is not on the parents' actions as cause of the child's difficulties, but on providing mutual support and information from a family perspective.

Parents who are interested in participating in a support or self-help group may contact the Federation of Families for Children's Mental Health for information on available groups, or for advice and assistance in organizing a new group. The Federation's address is 1021 Prince Street, Alexandria, VA 22314; telephone, (703) 7684-7710. Or, parents may contact PACER Center at 4826 Chicago Avenue South, Minneapolis, MN 55417; telephone, (612) 827-2966.

What Help Can I Expect from the School District for My Child with an Emotional or Behavioral Disorder?

Public Law 101-476

To begin to answer this complex question requires an examination of the Individuals with Disabilities Education Act, known as IDEA or PL-101-476. This law was formerly known as PL 94-142 or the Education of All Handicapped Children Act. The IDEA and its regulations specify those special educational programs that must be provided for students with disabilities by their school districts.

Special Education

The term "special education" under the IDEA means specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability.

A school district is responsible for determining whether a student has an educational disability as a result of the child's emotional problems. This determination may include a psychiatric or psychological evaluation conducted at a hospital or treatment center as well as behavioral and educational assessments conducted by the school. Based on this information, the school may need to develop an Individual Education Plan (IEP), which could include academic, behavioral, and social goals and objectives. Under PL 101-476, children with emotional or behavioral problems are served under the category of "seriously emotionally disturbed" (SED).

SED is defined as a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree which adversely affects educational performance:

- An inability to learn that cannot be explained by intellectual, sensory, or health factors.
- An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
- Inappropriate types of behavior or feelings under normal circumstances.
- A general pervasive mood of unhappiness or depression.
- A tendency to develop physical symptoms or fears associated with personal or school problems.

Special Education teachers with licensure in "emotional/behavioral disorders" (EBD)—Minnesota's terminology for children identified under federal criteria as seriously emotionally disturbed—have special training in how to teach students with emotional or behavioral disorders. Their basic role is to help design or provide instruction, case management, and support to a child with an emotional disorder within the education setting which accommodates his or her emotional problems.

The teacher must know how to shape the educational environment so that it is most conducive to the student's academic and social ability or performance. The student may require specialized curriculum to encourage academic progress. Finally, the teacher will use certain techniques designed to help the child's behavior become more productive, less destructive, and more likely to result in positive relationships with others.

Educational services for a child or adolescent would be provided in the least restrictive setting appropriate to the needs of the individual child. A school district can be expected to provide a full "continuum" of educational programs within its system. The full continuum offers arrangements ranging from placement in a regular classroom with consultation provided to the classroom teacher, to a full-time special education classroom. Often, small or rural districts work in cooperation with neighboring districts to develop the full continuum of services.

Related Services

PL 101-476 defines **related services** as: transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education. They include speech pathology and audiology, psychological services, physical and occupational therapy, early identification and assessment of disabilities in children, counseling services, and medical services for diagnostic or evaluation purposes. The term also includes school health services, social work services in school, and parent counseling and training.

For children and adolescents with emotional or behavioral disorders, the most likely related service would be a mental health service, such as counseling or therapy.

Included on the list of related services are **psychological services, medical services** and **counseling services.** The law does not mandate that each student with an emotional disorder be provided with counseling or mental health services; instead such supportive services are tied to identified or assessed needs, and must be provided to the extent that they support a special education goal.

The **psychological services** a school must provide are defined as:

- Administering psychological and educational tests, and other assessment procedures.
- Interpreting assessment results.

- Obtaining, integrating, and interpreting information about child behavior and conditions relating to learning.
- Consulting with other staff members in planning school programs to meet the special needs of children as indicated by psychological tests, interviews, and behavioral evaluations.
- Planning and maintaining a program of psychological services, including psychological counseling for children and parents.

Parents interested in ways in which a school may be expected to serve their child should keep the above list in mind. Often, psychological services encompass the first four items on the list and not the fifth, "planning and maintaining a program of psychological services, including psychological counseling for children and families." Psychological services may be provided by a **school psychologist**, or by other qualified school personnel, such as counselors or social workers.

If individual, group or family counseling is required by a child in order for him or her to benefit from a special education program, it should be discussed by the special education planning team and, if needed, included as a related service in the child's Individual Education Plan (IEP).

Counseling services for a child with special education needs means services provided by qualified social workers, psychologists, guidance counselors or other qualified personnel.

Such counseling might be provided by school staff or a district might contract with outside facilities, such as a community mental health center or a private consultant for counseling or therapy services.

Medical services under PL 101-476, as defined in the *Code of Federal Regulations* (Vol. 34, July 1988), means services provided by a licensed physician to determine a child's medically related handicapping condition that results in a need for special education and related services. School districts are not considered responsible for providing medical services by a licensed physician for other than diagnostic purposes.

Section 504

In addition to the specific rights provided to students and their parents under PL 101-476, parents need to be aware of the provisions of another federal law. Section 504 of the Rehabilitation Act of 1973 is a broader federal law than PL 101-476 in that it applies to any agency from which a person might receive services. Section 504 provides that no qualified individual with disabilities can be discriminated against solely on the basis of disability in any program or activity receiving federal funds. For a student with a diagnosed emotional disorder who may not qualify for

services under the IDEA (PL 101-476), but who still requires accommodations in the regular classroom in order to be successful in school, the right to those accommodations would be covered under Section 504.

THE INDIVIDUAL EDUCATION PLAN (IEP)

Understanding Assessment

School districts are required to evaluate (assess) a child before he or she can receive special education services. A comprehensive evaluation including formal and informal testing, observation, behavioral checklists, and information from parents is used to determine whether a child is in need of special education. Assessment identifies the specific needs and strengths a child has (present levels of performance), which form the basis for developing an IEP.

The law also requires that parents be invited by their child's school to attend and participate in a meeting with school staff to discuss the assessment results and develop a written IEP. Parents are encouraged to obtain copies of the assessment results before attending the IEP meeting, so that they are familiar with the results and have ample time in advance to consider their child's needs. Questions parents need to consider are:

1. **What positive behavioral interventions were tried by school staff to assist the student before referring him or her for an assessment?** Were those interventions carefully documented and evaluated? What were the results?
2. **Was the assessment of the child's functioning comprehensive? In other words, were all areas of concern evaluated?** While it is always important to consider the academic progress a child is making in school, his or her *educational* performance may also include the development of appropriate social, emotional, or behavioral skills. A child who is performing academically at grade level but who has no meaningful relationships with peers or adults may require special education intervention to address those areas.
3. **Was the child evaluated by more than one professional and in more than environment?** Were the child's behaviors rated in comparison to other students in the same classroom? Were parents involved in contributing information about their child's functioning at home or in the community? Has all relevant health information been discussed?

4. **Has a comprehensive academic evaluation been completed to assess learning problems which may be distinct from an emotional or behavioral disorder?** Children who have specific learning problems as well as EBD, may require services from a specialist in learning disabilities in addition to services from an EBD teacher.

5. **Has the student had, or will he or she need, a vocational assessment to determine work skills or talents?** Vocational education may be an extremely important component of a total educational program, both for developing specific work skills and, for some students, for acquiring appropriate social behavior and enhancing self-esteem.

6. **Do parents and school share a similar perspective of the child's needs? If not, what are the areas of disagreement? How will those disagreements be reconciled?**

It is important that parents understand the assessment results, and that parents and school are in agreement as to the child's needs. If the assessment is incomplete or inaccurate, the Individual Education Plan may not fully meet the needs of the student.

What Should Be Included in an IEP?

The IEP is a document that summarizes assessment results (including information provided by parents about their child and results from testing done outside the school), and states how the needs will be met (goals and objectives). An IEP should contain:

- The present level of performance (how a child is doing at the time of testing).
- A description of special education needs in the following areas: intellectual functioning, academic performance, communicative status, motor ability, sensory status, health/physical status, emotional and social development and behavioral skills, functional skills, and vocational, occupational and secondary transition skills.
- Long-term goals (one year) to meet the special education needs.
- Short-term objectives (steps for reaching the goals).
- The date of the IEP periodic review (to see what progress has been made toward meeting the goals).
- The adaptations, if any, that will be made by regular and special education to permit successful accommodation and education of a student into a classroom or other setting.
- A list of all special education and related services, the amount of time allocated to each service, and their starting dates.

QUESTIONS TO CONSIDER WHEN DEVELOPING AN IEP

The following questions are provided as a checklist for parents to consider when developing an IEP.

Where Will Services Be Provided?

1. **What placement is being recommended?** Have other placements been considered and dismissed? For what reasons? How much special education service will be provided, and in what settings (regular classroom, special classroom, alternative school site, community placement, nursery school)?
2. **How many other children will be in the special education setting(s)?** What are their ages and abilities? Will there be appropriate models for behavior? Are there other children performing at the same academic level?
3. **Is a behavior plan needed?** Who will develop the plan? Who will implement it? Is it individualized to meet the unique needs of one child or has it been developed for all children in the classroom? A child is entitled to a program that is tailored to his or her individual needs.
4. **How much time per day will be spent with children who do not have disabilities?** In what settings will this occur (lunch, recess, regular classroom, bus, etc.)? Will the child's behavior be a problem in those settings? If so, what will be done to help him or her to be successful?
5. **What support services will the school need to provide in the regular classroom for a successful educational experience?** These might include a positive behavior management plan, modifications to classroom environment, academic instruction tailored to the child's needs, a behavior management aide, or special books or materials.

Transportation Needs

1. **Will special transportation be necessary? Why?**
2. **How long is the bus ride?** How does that compare with the bus time for children who do not have a disability? Is the length of time reasonable?

3. **How will disciplinary problems be handled on the bus?** Will the child need an assigned seat? An aide? Who will transport the child to and from school if he or she is suspended from the bus but not from school? Who is the primary contact person if bus problems arise?

If a student's bus suspension results in missing school due to lack of transportation, the effect is to deny the child access to his or her special education program, a violation of Minnesota law. Parents will want to remember that transportation can be a **related service** and may be listed on the IEP.

In Minnesota, a student's home school district is responsible for transportation to care and treatment programs, including day treatment or chemical dependency programs. If the care and treatment program is located in another district, and the child continues to live at home while receiving such services, the district of residence (home district) is responsible for providing transportation to and from the care and treatment facility.

The home district is also responsible for covering the cost of educational services while the student is in a treatment facility; education may be provided in the treatment facility, in a district adjacent to the program, or in the home district itself, depending on the needs of the child.

The transportation regulations just described may not be in effect in other states; parents may call the Transportation section of their state Department of Education for the laws governing transportation for children in regular education settings, as well as for nonregular or special education settings.

School Rules and Policies

Many school districts, in an effort to maintain order and discipline within their schools, have implemented district-wide behavior management plans. The most widely used model of classroom management is a system called Assertive Discipline, a program developed in the 1970s by Lee Canter.

While reinforcing positive behavior is the original intent of the Assertive Discipline program, the guidelines also call for a system of increasingly restrictive consequences for occurrences of misbehavior in school environments. For example, a student who breaks a classroom rule may have his name placed on the chalk board. Additional offenses may result in a series of check marks on the board, leading to being sent to the principal's office or suspension from a classroom or school. While this type of program may be effective with many students, others may be excluded from the regular classroom environment because they are simply unable to adhere to often rigidly imposed classroom rules.

Schools that do not use a specialized behavioral intervention program will still have rules that all children are expected to obey. If a child with an emotional or behavioral disorder does not respond positively to the use of school disciplinary interventions (if the incidence of rule violations does not decrease), parents will want to meet with the school to write an individualized behavior plan for their son or daughter.

Questions to be considered are:

1. **Are there school rules and/or policies that will need to be waived or amended because of a child's emotional or behavioral disorder?** For instance, a school rule that all children show up for class with their pencils and books may be appropriate for most students, but may be unattainable within a normal time frame for a student with severe attention/memory problems.

2. **For rules which parent and school agree are appropriate, are the consequences for non-compliance acceptable?** If a child **does** forget to bring a pencil to class, what is the consequence? Is it reasonable? What will the child learn from the experience?

Most parents clearly want their child to follow rules established for all students. It can be difficult to decide which rules a student can or cannot follow, or what the consequences for not following the rules should be. An important point to consider when making this determination is whether behaviors which result in repeated time-outs, suspensions, or other negative consequences have **decreased** as expected.

Adaptations in Regular Education

Many children with emotional or behavioral disorders will spend at least part of their school day in a regular education classroom setting. Most will require some level of modification of the environment, teaching strategies, or coursework. An accurate identification of the student's emotional, behavioral, and academic needs will be necessary in planning a successful regular education placement.

For instance, a child with an acute anxiety disorder may need special encouragement to come to school. A reasonable plan might be for the student to obtain partial class credit just for attending school. He or she might benefit from a pass/fail grading system rather than the standard system.

If a child is able to attend school and is able to learn in the regular classroom, but because of an emotional disorder may not be able to complete the regular classroom work, the program should be modified to provide an opportunity for success. The curriculum can be modified or adapted, if needed, or replaced with individualized assignments related to the course.

A student with severe attention/memory problems may not be able to listen to a class lecture and simultaneously take notes; a copy of the teacher's lecture notes, or a carbon of another student's notes, could be provided without penalty to use as a study guide. Or, he or she might tape record the lectures.

Two sets of textbooks, one for home and one for school, can help teach responsibility for homework without penalizing the student for forgetting to bring books home each day. A printed copy of materials which have been presented on the blackboard or in filmstrips will insure that students who have difficulty copying such materials have them available for study.

Children with disruptive behaviors may have particular difficulty in the regular education classroom. A simple, clearly written behavior plan which parents, teachers, and the student agree is reasonable, should be developed **before** problems arise. Techniques used might include positive reinforcement, ignoring behaviors which are not seriously disruptive, or timeouts. Because parents and schools might not always agree on what constitutes a disruption in the classroom, this area should be thoroughly discussed at the time the plan is developed.

Parents and other members of the IEP team need to consider how the student's emotional or behavioral disorder will affect his or her performance during the entire school day – not just in special education classes – and write whatever accommodations are necessary in all regular environments into the IEP.

Suspensions and Expulsions

According to a 1990 ruling by the U.S. Office of Special Education and Rehabilitative Services (OSERS), schools that receive federal funds may not expel from services or indefinitely suspend students with disabilities However, repeated short-term suspensions remain one of the most widely used disciplinary interventions for students who have emotional or behavioral disorders. Most suspensions are for non-dangerous offenses, such as violating school or classroom rules.

In Minnesota, the Pupil Fair Dismissal Act defines the conditions under which Minnesota students can be suspended. The Act prohibits suspensions exceeding five school days at a time. Suspension cannot be extended for the same course of conduct or incident unless it is determined that the student continues to exhibit behaviors that create an **immediate and substantial** danger to others, self, or school property. Students who at the end of five days are not found by the IEP team to be dangerous must be readmitted to school. For a student with an emotional or behavioral disorder, the decision to **extend** a suspension should not be made without convening a meeting to decide whether the child continues to exhibit *substantially* dangerous behavior. Suspensions cannot be extended beyond ten school days.

Other states may have similar laws or they may have laws that permit suspension for up to ten days. However, students receiving special education services for emotional/behavioral disorders may not be suspended for a period in excess of ten days.

Parents and school staff should thoroughly discuss the issue of suspension at their child's IEP meeting, including its educational relevance for specific offenses. A student should not be suspended for non-dangerous behaviors which are directly related to his or her emotional or behavioral disorder (verbal abuse to staff, etc.) unless the school and parents agree that suspension is an appropriate intervention. Federal law prohibits exclusion from participating in or granting an unequal opportunity to participate on the basis of a disability (34 CFR 104.4).

Any behaviors which parents and school agree will result in out-of-school suspension (OSS) should be listed on the IEP; general statements such as "not following school rules" should not become a rationale for suspension.

A child or adolescent should not be repeatedly suspended for the same behaviors, and should not be suspended for behaviors which are clearly beyond his or her control, unless such behaviors create an *immediate and substantial* danger to others, self, or school property. Slamming a locker door would not meet the test of *substantial* danger.

In-school suspension (ISS), when a student is removed from his or her classroom program and given school assignments to complete in a designated setting, is frequently used as an alternative to out-of-school suspension (OSS). This arrangement needs to be viewed with caution if it occurs frequently.

Whether ISS is appropriate for an individual student really is a question of educational judgement. If a student with an emotional disorder is placed in ISS using the disciplinary procedures applicable to all students without consideration of the individual educational needs, such placement would clearly constitute discrimination on the basis of a disability.

Parents who are concerned about suspension may want to consider the following questions when developing their child's IEP:

1. **What is the educational purpose of suspension?** How will it help a particular child to learn more appropriate behaviors? What alternatives can be used to out-of-school suspension (OSS)? Will in-school suspension deny a child access to his or her instructional program, including any related services? Frequent in-school suspensions that do not decrease over time should signal both parents and schools that the student's program is not meeting his or her educational needs.

2. **What are the state rules concerning how many times suspension can occur, or for what length of time?** Long-term suspensions in excess of ten days, including in-school suspensions, represent a "significant change in placement" under the federal law, requiring parental consent. Parents who object to a proposed change of placement are entitled to a formal due process hearing to contest the proposal; their child's placement cannot change without their consent as long as they are in the due process system.

3. **Will suspensions for the child with an emotional disorder be based on normal school policy?** Are there rules which discriminate against the child because of his or her emotional/behavioral problems? How will those rules be individualized? An IEP meeting may be held following each suspension, to discuss whether other interventions should be tried, and to make changes in the IEP, if needed, to address the behaviors which resulted in the suspension.

If suspensions **are** used, they should serve the purpose of providing a useful learning experience for the child or adolescent. If parents agree that suspension is a valid instructional tool for their child, they should evaluate whether, over time, the behaviors which resulted in suspension actually **decrease.**

Readers with an interest in examining legal issues related to suspension and expulsion can find several excellent and highly readable articles in the February, 1991, *Exceptional Children* magazine. Dixie Snow Hueffner, an Associate Professor in the Department of Special Education at the University of Utah, Salt Lake City, and Mitchell Yell, a Doctoral Candidate from the Special Education Department at the University of Minnesota, provide a "Point/Counterpoint" perspective of recent court decisions.

Considering the Need for a More Restrictive Placement

In the past, there has been a tendency to segregate students with emotional or behavioral disorders from regular classroom environments. While there **may** be times that a child's behavior or emotional state is such that a very structured setting is the only place where the child can function appropriately, such restrictive placements should be used only when it is clear that the student's needs are such that a less-structured environment is not appropriate. The intent of the federal law is to insure that children have access to an appropriate level of services to meet their individual needs.

Parents who are concerned about a school's proposal to move their child to a more restrictive setting or program should discuss the reasons for the proposed move before making a decision. It may be useful to know what interventions the school has used in trying to maintain the student in a more normalized setting, and to know what worked or did not work. Questions parents need to ask are:

1. **What *specifically* are the problem behaviors?** Vague descriptions, such as "acting out" or "disrespectful," are not useful statements in identifying problem behaviors. Often different teachers may have different tolerances for the same behaviors; what constitutes disrespect in one classroom, for instance, may be ignored in another.
2. **Has the school collected data on the problem behaviors?** Has information been gathered on the student's behavior compared to other students in the classroom? Has the behavior been rated in a variety of environments, or just in the class where he or she has the most difficulty? If a child is having problems only in one classroom and nowhere else, could the problem be with the size of the class or the interaction between the student and the teacher?
3. **What interventions have been tried to correct the behavior (modeling, rewards or incentives, time-outs, modified curriculum, etc.)?** What worked? What did not? What else could be tried in the current placement?
4. **Does the child have the same problem behaviors at home?** Is the cause of the behavior known? How do parents handle the behavior?

CAUTION: Sometimes parents believe that if their child has problems at school but not at home, the school must be doing something wrong. Children are often under greater stress at school than at home and may respond differently than parents would expect.

However, any severe behavior problems that arise at school but are never a problem at home need to be discussed with the IEP team. Parents can be a tremendous resource to schools in identifying techniques that school staff might try with their child.

Sometimes parents may agree that their child needs more special education services or a more restrictive setting but are not sure that what the school is recommending is appropriate. Before agreeing to any proposed program, parents may arrange to visit the setting, preferably while school is in session. Parents also may talk with the teacher about the program being recommended. Question parents may want to ask are:

1. **Can a child be placed in a program for a trial period of several weeks or a month?**

2. **How long does the average student in the new program stay in that setting?** Do most students transfer back to their home schools or districts? If the program is in a separate school, will a transition plan be developed to allow the student to re-enter his home school successfully?

3. **Does the new program have rules that need to be individualized for the child?** For example, a rule stating that a student may be physically "patted down" or searched if drug use is suspected may not create a problem for some students, but could be devastating for a child who has been physically or sexually abused.

   Parents who are considering a transfer for their child to a new setting may obtain a copy of the program rules and discuss with program staff any that they believe will discriminate against their child and which rules may require modification.

4. **Is the academic program appropriate? Comprehensive?** Are there special skills that a child has developed in school (sports, band, etc.) that are not available in the new setting? How will those needs be met? Is the new program on the same quarter or trimester schedule as the home school? What will that mean for the transfer of credits?

5. **If the student is in high school, what are the opportunities for vocational assessment? Training? Work experience?**

6. **What are the criteria for leaving the program once a student is placed?** Some children are unable to "earn" their way out of a segregated or very restrictive special education program, even when they and their parents believe they can be successful in a less restrictive setting. The IEP team decision, not simply the attainment of a specific program criterion, should determine whether a student is ready to return to a more normalized school program.

7. **How often will the team sit down to review the effectiveness of the placement? Will parents be invited to each review?**

RESIDENTIAL PLACEMENT

The School District's Responsibility

When a district has the full continuum of services in place, a student would be placed in the least restrictive (more normalized) setting in which he or she can be successful. If the child's emotional disorder is so severe that he or she cannot function in any of

the school's settings, consideration should be given to placing the child in a day treatment or a residential setting where both an educational program as well as needed treatment could be provided.

In those situations where the school district is making the placement for educational reasons, they would be responsible for assuring that the education, board and lodging, and transportation would be provided at no cost to the parent.

If such placement is made by nonschool personnel for treatment and not for educational reasons, the school district's responsibility would extend only to paying for the educational services for the child, and not for the costs of room and board or medical treatment. Clearly, several strong and possibly conflicting forces are in operation:

- Parents, understandably, can argue that if their child needs psychotherapy or another type of intensive therapy in order to learn, then that therapy should qualify as a related service, which the school must provide. Or, if the student needs placement in a residential facility in order to progress educationally, then the costs of placement should be the school's responsibility.
- Schools may suggest that psychotherapy or other types of intensive therapies are not "educational" but rather are "medical treatment." Therefore, they may believe that they should not be required to deliver those services.

What the Courts Say

The courts have addressed the issue of what constitutes an educational versus a medical placement with somewhat mixed results.

In ***Taylor v. Honig*** (1989), a three-judge panel of the Ninth Circuit Court of Appeals ruled that a California school district had to pay for an out-of-state residential placement for a student because his "social, emotional, medical, and educational needs are not severable and are intertwined." The school district had argued that because the Texas facility where the student was placed provided medical services, the cost was not an educational responsibility. The appeals court held that because the facility operated as a school as well as a psychiatric hospital, the placement could be considered an educational one. The Ninth Circuit Court also upheld the district court's order to examine the possibility of splitting educational and medical costs among state agencies.

A second case, also heard by the Ninth Circuit Court of Appeals, ruled that schools are not responsible for funding if the treatment of children with mental illness is focused on alleviating a psychological problem.

In ***Clovis Unified School District v. California Office of Administrative Hearings*** (1990), the court gave its own criteria for determining whether the child's placement was a **residential placement** or a **medical service.** The court held that the ultimate purpose of treatment would be the deciding factor in making the determination.

If the placement and treatment was for a *fundamentally educational problem*, it would be covered under PL 101-476 as a **residential educational placement** and **related services**; but if the placement and treatment was for a *fundamentally medical* (including psychological) *problem,* it would be considered a **medical service.**

Because the program chosen by the parents in this case provided six hours of psychotherapy, but did not provide the student with educational services (as distinct from the *Taylor v. Honig* case mentioned earlier), it was clearly a "medical" placement, and thus not a related service under PL 101-476. The Clovis court provided helpful reasoning for making the distinction between educational services and medical services. As stated in the decision:

> . . . a student who must be maintained on kidney dialysis certainly cannot physically benefit from education to the extent that such services are necessary to keep him alive, but again, it is not the responsibility of the school district to provide such maintenance care. All medical services are arguably "supportive" of a handicapped child's education; therefore mere "supportiveness" is too broad a criterion to be the test for whether a specific service is necessary under the Act to assist a child to benefit from special education.
>
> . . . the analysis must focus on whether placement may be considered necessary for educational purposes, or whether the placement is a response to medical, social or emotional problems that is necessarily *quite apart from* the learning process [italics added].

As a practical matter, parents should remember that their school district is responsible for educating their child. When the school has tried various settings and programs for the student and he or she has not made progress, the district's obligation to the child is to continue to explore alternatives – including day treatment programs or residential treatment – and to provide such programs at no cost to parents when they are necessary to meet the child's educational needs.

Educational Services

Not all students who are receiving mental health services in a residential setting need special education or related services. All, however, are entitled to an appropriate educational program, including children in temporary placements, such as **shelter care** placements.

Attitudes toward providing educational services vary widely among residential facilities. Some may try to maintain a student at or near the regular grade placement level while providing intensive mental health services. Others may believe that education is not very important at a time when a child may be in crisis, and provide only minimal educational services.

Especially with adolescents who may need to accumulate credits toward graduation, the educational program in a residential placement should be carefully monitored. It can be traumatic for a student who is returning from a residential facility to his home school to find that he or she will have to repeat a grade because the coursework was not offered in the residential setting, or that the school work completed in the facility will not be accepted by the home school district. Questions parents may want to ask are:

1. **How much time each day will be spent on academic instruction?**
2. **Is the teacher specially licensed to teach children and youth with emotional or behavioral disorders?**
3. **What subjects will be taught?** Are the textbooks used part of the general school curriculum or are they materials compiled by the institution? Are the content areas similar to what the student would be getting in his or her school?
4. **Are there areas in which the student needs to earn credits?** Has a discussion taken place with the local school regarding what credits they will and will not accept, based on the curriculum offered?
5. **How will the residential facility obtain a copy of the IEP?** Who will be responsible for implementing it? Will there be a daily or weekly evaluation of the educational placement?

Returning to School

Careful planning is necessary for students returning to their home school after release from a residential placement. Parents need to know when a release from an institution or other residential setting is anticipated in order to begin planning the transition well in advance of its occurrence. Questions parents will want to consider are:

1. **Will the reentry into school from a residential placement be on a full-time or on a part-time basis?**
2. **Will a staff person from the residential setting attend the IEP meeting to help plan a successful return?**
3. **Has the residential facility kept a careful record of credits earned or credit hours accumulated?** Will they make a written recommendation for a promotion in grade? Have they listed activities

in such a way that the school can understand how those activities may translate into credits? For instance, a swimming or camping skills program could be written as "physical education," group participation in counseling or other activities might serve as "social studies" credit hours, or operating a cash register at a job site could substitute for a "basic math" curriculum.

4. **How will the records be transferred from the residential placement to the public school setting?** If possible, parents may want to "hand carry" a copy of the records to the school in order to to avoid unnecessary delays in placement or in developing a school program.

5. **Has a homebound program been proposed as an interim placement?** Most students with emotional and behavioral disorders have needs in the areas of social or peer relationships which clearly cannot be met when they are not in school.

   Sometimes students are placed on "homebound" programs (an hour or more per day of services provided at the child's home) following a residential placement, while the home district locates or develops an appropriate program. Clearly this practice may not be in the best interest of some students, and should not be necessary if the IEP planning team meets well in advance of the scheduled release date. If parents do agree to a temporary homebound program, that placement requires formal parental consent and a signed IEP.

   A homebound placement should be for a limited period of time, usually not more than several weeks, unless parents agree that their child's needs are such that a homebound program constitutes the least restrictive setting.

6. **Will a support system need to be identified for the child returning to his or her school after a long absence?** Even for students who are not receiving special education, having an identified support person available when problems occur can be a critical component of a successful transition plan. It is not imperative that the person identified be one of the child's teachers, as long as it is a person who will provide support to the student and serve as his or her advocate in the school setting.

Communicating with the School

Partnerships, even very good ones, are dependent on clear communication between partners. Developing a communication plan between home and school in advance can help reduce misunderstandings. Questions to consider are:

1. **What kind of communication will be established with the school regarding a child's progress?** Will the teacher call at a scheduled time? Send written reports? If a child has more than one teacher, who will be the primary contact person?
2. **How will parents know if their child is keeping up with classroom assignments?** Who will monitor his or her academic progress, especially in the regular education settings? Will it be daily? Weekly?
3. **How will the regular education teacher(s) be informed about the child's academic and behavioral needs?** Who will modify the curriculum or develop alternatives to the regular assignments when needed?
4. **Will the regular education teachers receive a copy of any behavior management plan?** Are they aware of the rules or policies that the child may be exempted from, or which will need to be modified? Do they have a set of written classroom rules that need to be discussed and adapted to the student's needs?
5. **Who normally makes decisions regarding disciplinary measures, such as detention or suspension?** It is very important that the professionals (often the principal or the assistant principal) who enforce the school rules are aware of any special behavior program that has been developed for an individual student with an emotional or behavioral disorder. Those individuals who are responsible for maintaining discipline in the schools should be involved, if possible, in helping to develop successful interventions for problem behaviors.
6. **How will the school communicate with the parent?** How frequently? What procedures are to be used in an emergency situation? What does the school view as an "emergency plan?" Many parents report having been called at work three or four times per week when their child was a problem at school. It is important to be clear about what information the school **should** or **should not** communicate to parents during the course of a school day.

EVALUATING THE IEP

What Happens After an IEP Meeting?

After the IEP meeting, the agreed-upon goals and objectives will be developed as a written document and mailed to the parents for consideration. At this point, it may be wise to do a final check before agreeing or disagreeing with the program. Questions parents will want to ask are:

1. **Are each of the needs, as defined in the assessment, addressed as goals on the IEP?**
2. **Does each stated goal have one or more objectives that are short-term, specific, and measurable?**
3. **Are the starting dates listed for each service? The date of review?**

An IEP must be written once a year and reviewed at least once during the year. Parents who want to be included in the review meeting should notify the school that they want to be invited to attend. They also need to let the school know what specific days and what times of day work best for them to attend a meeting; the time should be agreeable to both school and parents.

Measuring Progress

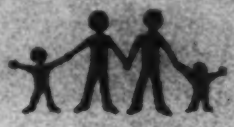
The purpose of developing goals and objectives in an IEP from assessed needs is to provide an opportunity for the student to make reasonable progess. A successful special education experience is measured by the progress a child or adolescent makes in achieving the goals and objectives on his or her Individual Education Plan.

An IEP can form the basis for a successful school program for children and adolescents with emotional or behavioral disorders. When developed in conjunction with parents and the mental health professionals who work with their child, an IEP will define the support and structure needed by a student, as well as the approach to be used in providing educational services.

It is important for parents to understand their rights and responsibilities in developing an educational program for their child because public schools play a vital role in the social and emotional development of their child.

NOTESNOTESNOTES

What Is My Role as a Parent in Planning Services for My Child?



Like children with other disabilities, a child or adolescent with an emotional disorder is probably going to have more than one professional or agency involved in his or her life.

One of the major roles that parents assume is to try to coordinate the services provided to a child. Parents are the continuing presence in the life of a child; while professionals pass in and out of his or her existence, parents have the experience of remembering events and services over the course of a child's life. In an ideal service system, professionals from the multiple agencies (school, mental health center, community corrections, health, etc.) would be talking with one another and exchanging information on what's happening with a particular child, and what each agency might be doing to help the effort of the other(s).

In real life, however, unless a child has a competent professional "case manager," there may be no coordination among agencies unless parents serve as the link between service providers.

Coordination among and between service agencies is not only cost effective in that it prevents unnecessary duplication of services, but may greatly enhance a child's total mental health program by providing a consistent approach to treatment across environments. It is difficult to overestimate the value – or at times the difficulty – of coordinating services. Parents who do not have access to case management services, and who find that the professionals in their child's life appear to be working in isolation – or even against each other – may want to arrange a meeting with representatives from the school staff, from each outside agency and possibly from a parent support or advocacy organization, so that communication is clear and efforts coordinated.

Parents will need to carefully monitor their child's school program and be sure that the level of service is appropriate to the assessed needs. They will need to evaluate their child's therapy plan for continuing emotional and behavioral progress. Parents are also responsible for monitoring the positive or negative effects of a medication regimen and reporting those effects to the child's physician.

When children receive services in more than one area (for example, education and counseling) meetings or telephone contacts between the professionals who work with the child may enhance the success of both programs. Professionals from different disciplines who work together to help a child may also find that there is much to learn from one another.

New models of addressing the mental health needs of children and adolescents with emotional disorders are based on family strengths – the understanding that families are

vital to the well-being and continuing health of their children. Most parents know their children better than professionals do. The information that a parent knows about his or her child – regarding health, relationships, school performance, likes, dislikes, fears and accomplishments – is vital to developing a service plan that addresses the needs of the whole child.

Some Financial Considerations

One of the most frustrating aspects of seeking appropriate mental health services for a child is finding programs that families can afford. Few programs or services are free. Unless private funds are extensive or parents have a comprehensive insurance policy, other financial sources must be sought. Because each person's financial situation, each insurance policy and each treatment program's eligibility criteria are relatively different, once again, no universal answers can be provided that will apply to each specific situation. Here, however, are some financial suggestions and, equally important, some pitfalls to avoid.

Insurance Policies

Group health policies written under Minnesota law for groups composed of Minnesota residents must provide for mental health coverage. Generally, they will at least partially cover the costs of treatment through a hospital program, community mental health center, a residential treatment center, or a psychiatrist or licensed consulting psychologist.

Many such plans include out-of-pocket costs above the monthly premium in the form of co-payments, deductibles and excess costs the plan may not cover fully, if at all. Before committing to an expensive treatment program for a family member, parent should make absolutely certain that their policy does have the coverage needed. Policies written for individuals (non-group coverage) may vary a great deal; their specific provisions should always be carefully examined. The advantage of a private individual or group policy is that, generally, parents have a wider range of providers to choose from than under other plans. Such freedom of choice, however, is not inexpensive.

Questions about specific legal provisions regarding insurance policies may be addressed to the state regulatory agency for group insurance policies. In Minnesota, the regulatory agency is the Department of Commerce.

Health Maintenance Organizations, or HMOs, represent a prepaid type of insurance plan. The monthly premium pays for all services covered under the plan "in advance," so there are no unexpected medical bills. However, patients may be asked to pay partial fees for some medical expenses, such as prescriptions. Mental health fees are frequently not fully covered under an HMO plan; it is not unusual for families to assume a large percentage of the cost of mental health treatment for family members. HMOs are also

governed by a regulatory arm of state government, to whom written complaints about insurance coverage should be submitted. The agency governing HMOs in Minnesota is the Department of Health.

Even though parents may know they have insurance coverage, in general, the therapy or treatment program being considered should be reviewed to make sure it's eligible. A rule of thumb is that the more medically-oriented a program is, the more likely its eligibility for coverage. Programs conducted by psychiatrists or licensed consulting psychologists have a better likelihood for insurance reimbursement than ones run, for instance, by social workers with bachelor degrees. Programs run by hospitals, even in cases where hospitalization is not required, may be eligible. The state mental health agency will be able to provide information to families about which services may be reimbursed by insurance.

No matter what type of insurance coverage a family chooses, it will be important to carefully read the section on mental health coverage. It's also a good idea to learn the appeal process for a particular policy if parents feel their child is being denied necessary services.

Supplemental Security Income (SSI)

On February 20, 1990, the U.S. Supreme Court ruled in *Sullivan v. Zebley* that applying a tougher standard for determining disability to children than adults was not legal. The law had said that adults can receive SSI if their impairment makes it impossible for them to do "substantial" work. However, only children who were poor and met specific criteria, such as deafness or mental retardation, could receive SSI.

The Court said that children who are poor and have disabilities should receive SSI if their disabilities are comparable to those that would prevent an adult from working. For instance, the impact of an impairment on the normal daily activities of a child—speaking, washing, dressing, feeding oneself, going to school, playing, etc.—would be comparable to assessing the impact of an adult's impairment on his ability to perform substantial gainful work. Children who, because of a severe emotional disorder, are unable to perform the normal daily activities of childhood may be eligible for SSI under the newly expanded definition of eligibility. Parents may call 1-800-234-5772 for more information about SSI.

Medicaid–Medical Assistance (MA)

What if a family's income is high enough to exclude them from receiving any kind of government income assistance, but too low to handle the cost of medical care for a child with an emotional disorder?

Families might want to find out if their child could qualify – not for an income assistance program – but for Medical Assistance (Medicaid or MA) to help handle the cost of necessary treatment. Though it's the child's costs that are a concern, it is the parent's income that is taken into account when determining eligibility. This possibility may be explored by inquiring through county human or social services departments.

TEFRA (Section 134 of the Tax Equity and Fiscal Responsibility Act of 1982)

Another way of qualifying for Medicaid when the parents' income is too high is to apply for MA under TEFRA. The TEFRA option provides MA eligibility for home services for certain children with disabilities who live at home with their parents and who would not otherwise be eligible because of parental income and assets.

Minnesota's progam under TEFRA is known as the Children's Home Care Option (CHCO). In order for a child to be eligible for medial assistance under this option, he or she must be eighteen years of age or younger, able to get MA if he or she were in a medical institution and need the kind of home care comparable to that provided in a medical institution. The cost to MA cannot exceed the cost of institutional care.

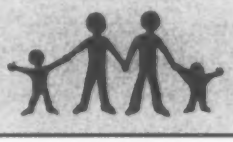
Parents of children who qualify under the CHCO assistance program can expect to contribute a fee based on their income to help cover the cost of services.

CHCO is presented as one model of providing MA eligibility to children; other states will have differing sets of regulations. Parents who need financial assistance but whose child does not qualify for Medicaid, should call their Medicaid office and inquire about eligibility under TEFRA.

What kind of programs might be covered under Medical Assistance? The general guideline is: those most medically oriented; i.e., most hospital-based programs; some, but not all community mental health programs; and services from private doctors.

The types of programs that can be covered are periodically reviewed and reassessed. Courts are reexamining the eligibility of certain programs, and the federal administration has granted certain waivers that allow some programs that would not have been eligible in the past – including schools – to receive Medicaid reimbursement now. Therefore, it is always a good idea to check in advance whether or not the program in which parents are interested might be, or might become, a Medicaid-enrolled provider.

A Father's Story



Written by a Father

Most of us are familiar with the military term "no man's land "(NML), which is defined as an "indefinite area of operation, involvement and jurisdiction between two conflicting sides."

I am a psychologist who has spent most of his fourteen-year career working with children and families. I am also the parent of a ten-year-old child with a diagnosis of "pervasive developmental delay." A role conflict like that meant a lot of early hiding in an emotional NML (any resemblance between the abbreviation for "no man's land" and "normal" is purely coincidental!).

A few examples of my thinking over the years will illustrate what spending time in NML is all about: "If she were a client who did that instead of my own child, would I have reacted in the same irrational way?" (operation); "I have to deal with that stuff all day at work, dear. I don't want to deal with it when I come home" (involvement); "I help all of those other kids, and I can't 'fix up' my own child" (jurisdiction).

During those early years, being in NML was manifested by periods of physical and emotional inaccessibility on my part (lots of sports and work), denial ("she'll probably outgrow it") and projection of blame and displacement of anger towards my wife. ("If you would only be more relaxed when you're around her. . . . You were the one who wanted a second child. I was content to stop after one.")

The denial aspect was the hardest to pull off because by the time our daughter was six to twelve months old, she was showing some very atypical behavior, some of which was autistic-like. I remember, at the time, flashing back to early graduate school days when I had seen many children diagnosed as autistic. I recall sharing commonly held fears with my fellow students about how would or could we deal with the daily traumas of parenting a child like "that." Keep in mind, too, that in those days, "poor" parenting was considered in many circles to be a major contributing factor to the development of autism and related disorders.

By the time our daughter reached late preschool/early school age, I was becoming known as "someone who did good work with kids." However, our daughter was also becoming well known, though for different reasons.

A situation which I have titled, "You Could Hear a Pin Drop in the Grocery Store Incident" will serve as a good illustration. At the time, our daughter was in the habit of screaming for no externally apparent reason. One day, she and I were grocery shopping when she let out with a shriek. After that, the only sound you could hear was the Musak. Unfortunately, this was one of the first times when both the parent and the psychologist had to face the Musak together. In addition to the stares of other shoppers, who should be coming around the corner but the mother of a family I was working with! She asked, "What's the matter?" and I replied with considerable humility, "I don't know; she frequently does that."

The battle in me had been joined. The opposing sides (parent/psychologist) had converged. There was no more NML to go to. It was no longer possible, at any level, to deny the problem. Emotional inaccessibility was a sure ticket to the divorce court and/or the therapist's office. I would have needed a lobotomy in order to continue projecting guilt or displacing anger towards my wife.

During those years, it was finally necessary to come to terms with a host of "parent" issues, including:

- Questions about where I might have failed my daughter during her infancy and toddler years.
- Angry feelings towards her, including a wish she had never been born.
- Scapegoating (blaming her for family disharmony).
- Paranoia (real and not so real—wondering why the neighbors avoided us).
- Unfair comparisons with siblings and other children, feeling judged by "society."
- Searching for the Holy Grail (magic cure), ad infinitum, ad nauseam.

As a psychologist, there were a number of related, but nonetheless unique issues which also needed to be addressed. Some of those included:

- Internal role (parent vs. psychologist) conflict, especially at school staffings both for my own child and for my clients.
- Questions about how my own child's problems might affect my practice as far as referrals were concerned.
- Wondering what my professional peers thought of me.
- Doubts about how much credibility I or anyone else should give to any "professional opinions" I might have about our daughter.

- Sadness after being of help to some other family and yet unable to "cure" my own daughter, etc.

Therefore, while there may be some advantages to being a psychologist/parent of a handicapped child (for example, having professional "connections" and a more sophisticated knowledge base), it is really a toss up as to whether those factors totally counterbalance the disadvantages. Furthermore, there are situations where knowing too much (for instance, about a long-term prognosis or the "politics" of a parent-teacher staffing) can – at best – leave you feeling powerless and – at worst – leave you in a state of paralyzing rage.

In conclusion, I would like to offer a brief and admittedly incomplete list of suggestions, which many readers will already find familiar.

1. We all know there are certain undeniable truths, such as the sky is blue, the grass is green, we all die, and we all pay taxes. I would like to add a couple more. First, there is no Holy Grail. However, keep searching. It will sharpen your survival skills. Second, there is no "free lunch," PL 101-476 notwithstanding.

2. It is easy to fall into a vicious, repetitive cycle, where, in relation to your child, you vacillate between three roles, which are:
   - Victim ("This kid makes me feel so burned out").
   - Persecutor, where the feelings of hurt associated with being a victim are transformed into irrational, angry overreactions toward your child.
   - Enabler, where the overwhelming guilt derived from your overreaction leads to overprotection of your child from outside forces (school, relatives, neighbors) or to granting your child's undeserved or unwarranted requests or demands. This, in turn, serves to foster or reinforce the occurrence of further abnormal regressive behavior which will eventually lead back into the hurt-anger-guilt cycle.

3. Use humor to lighten the anguish. My wife's early diary of our child's behavior would have Erma Bombeck in stitches. For example, one of our daughter's favorite idiosyncratic expletive was "flat rabbit," which, when younger, she would yell when frustrated. One day in a restaurant, my wife told her to order the rabbit so she could "eat a flat rabbit." Everyone, including our daughter, thought it was hilarious. Other than occasional joking about the restaurant situation, we never heard her use that expression again.

4. Figure out what your child's capabilities are and multiply by two. Inadvertently, it may have become easy to underestimate your child's strengths. To counter the underestimation means taking a lot of risks, including risks of public embarrassment or disapproval, as well as self-esteem risks to your child. Take them anyway, and trust your judgement. There is a very fine line between high versus unrealistic expectations. If you are going to err, do so on the side of unreality. Your child won't go crazy, and chances are you won't either.

5. Within your family, stay constantly aware of each other's needs and don't hesitate about being honest with regard to how much support you need and how much support you have left to give. However, chronic chest beating is not allowed. Having very supportive friends and/or family, especially if they have children, is also crucial for the maintenance of your sanity.

6. When you see or hear your child doing something, don't automatically assume that it's abnormal, bizarre, or strange. Living with a child with a disability means you're constantly being exposed to unusual situations and, therefore, always assuming the worst. Don't feel bad though. Mental health and special education professionals have the same problem. Like yourself, they are also overexposed to abnormal situations and may tend to link any behavior to a handicap.

7. Attempt to turn liabilities into assets. (For instance, screamers' nodules create very deep, throaty, resonant voices.)

8. As a parent, you remain one of the best sources of information and ideas. Avoid the double bind of feeling put upon and scared when the professionals start asking for your opinion or angry and ignored when they don't. Dictate. Don't abdicate.

Looking at the Future

One of the greatest needs for children with emotional disorders and their families is for strong statewide organizations or groups specifically designed to address and try to overcome the problems still existing in the field of children's mental health. These problems include the:

- Continuing lack of adequate mental health services and programs in many states.
- Dramatic underfunding by states of mandated services to children and their families.
- Need for parent and family support groups to help parents deal with the stigma still too often associated with children who are behaviorally different, and with the specific difficulties of dealing with such children.
- Need for respite care services.
- Development of a true continuum of family and community based services designed to prevent unnecessary out-of-home placements.
- Need for special education programs to fully implement the mandates of PL 101-476, including the provision of appropriate related services for children and adolescents with EBD.

In 1988, five states received grants to undertake the organization of parent networks designed to impact the way services are provided to children and adolescents with emotional/behavioral disorders and their families. In 1990, the number of parent organizations funded was fifteen.

Over the next several years, services to children and adolescents with emotional or behavioral disorder in the nation are expected to be more readily available to families than at any time in the past. The CASSP grants to states from the National Insititue of Mental Health have set the stage for state level collaboration among agencies responsible for children's services. The development of strong coalitions of parents of children with emotional/behavioral disorders – locally, at state levels, and nationally – is emerging and will continue to grow.

History has shown that great strides have been made in other disability areas when parents organized and recognized that their children's needs are shared with many others and that solutions come more easily when pursued by a group.

Many parents and caring professionals are already advocating for children with emotional/behavioral disorders. By joining together, rather than by struggling alone to find elusive answers, parents can better address gaps in services.

Parents who are interested in speaking with other parents in support groups, or who are interested in organized advocacy efforts to improve services in their own communities or states, may call any of the parent organizations listed in the Appendices of this book. Or, they may call the EBD Project at PACER Center for referral to groups within their own geographic area. PACER's telephone number is (612) 827-2966.

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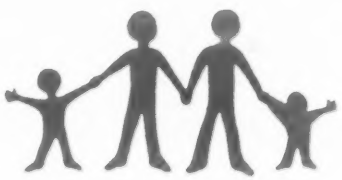
APPENDICES



Appendix A: Organizations Concerned with Children's Mental Health

NATIONAL ORGANIZATIONS

PARENT ORGANIZATIONS

Federation of Families For Children's Mental Health (FFCMH)
1021 Prince Street
Alexandria, VA 22314
(703) 684-7710

National Alliance for the Mentally Ill, Child and Adolescent Network (NAMI-CAN)
1901 North Fort Meyer Drive, Suite 500
Arlington, VA 22209

National Parent Network on Disabilities
1600 Prince Street, Suite 115
Alexandria, VA 22314
(703) 684-6763

PROFESSIONAL ORGANIZATIONS

Child and Adolescent Service System Program (CASSP)
National Institute of Mental Health
Parklawn Building Room 7C-14
5600 Fishers Lane
Rockville, MD 20857
(301) 443-1333

Children's Defense Fund
122 C Street NW., Suite 400
Washington, DC 20001

Council For Children With Behavior Disorders (CCBD)
(A Division of Council for Exceptional Children)
1920 Association Drive
Reston, VA 22091
(703) 620-3660

National Clearinghouse for Mental Health Information (NIMH)
11A-33 Parklawn Building
5600 Fishers Lane
Rockville, MD 20857
(301) 443-4513

National Information Center for Handicapped Children and Youth
P.O. Box 1492
Washington, DC 20013
(703) 893-6061

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314
(202) 783-0125

Appendix B
Additional Reading

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Appendix C
Statewide Parent Organizations *
For Parents Whose Children Have Emotional or Behavioral Disorders

ARIZONA

Mentally Ill Kids in Distress
3627 E. Indian School Rd.
Suite 107
Phoenix, AZ 85018
Marilyn Racer, Project Coordinator
Sue Gilbertson, Project Director
(602) 381-1591

GEORGIA

Georgia Parent Support Network
1559 Brewer Blvd., S.W.
Atlanta, GA 30310
Sue Smith, Parent Coordinator
(404) 753-3858, (404) 756-0187

HAWAII

Mental Health Association in Hawaii
200 N. Vineyard Blvd., Suite 507
Honolulu, HI 96817
Barbara Wood, Project Coordinator
(808) 521-1846

KANSAS

Keys for Networking, Inc.
700 S.W. Jackson
Jackson Tower Suite 100-A
Topeka, KS 66603
Robert Dyche, Outreach Counselor
(913) 233-8732

MINNESOTA

PACER Center, Inc.
4826 Chicago Ave. S.
Minneapolis, MN 55417-1055
Dixie Jordan and Ellen Neuman, EBD Project Coordinators
(612) 827-2966

MISSISSIPPI

Mental Health Association of the Capital Area
5135 Galaxie Drive, Suite 302C
Jackson, MS 39206
Beth Scarbough, Executive Director
(601) 982-4003

MONTANA

Parents, Let's Unite for Kids
EMC/IHS 1550 N. 30th Street
Billings, MT 59101-0298
Katharin A. Kelker, Project Director
Barbara Sample, Parent Coordinator
(406) 657-2055

NEBRASKA

Nebraska Family Support Network,
AMI-NE
Route 1, Box 3
Inavale, NE 68952
Cynthia S. Eckhardt, Parent Coordinator
Jean Cookson, Assistant Coordinator

NEW MEXICO

Parents for Behaviorally Different Children
1720 Louisiana N.E., Suite 204
Albuquerque, NM 87110
Michelle Chapman, Project Coordinator
(505) 256-3100 a.m.
(505) 255-7634 after 1:30 p.m.

NEW JERSEY

Mental Health Association in New Jersey
75 Scotland Ave.
Albany, NY 12208
Karen Harbour, Administration Coordinator
Virginia Wood, Parent Coordinator
(518) 434-0439

NORTH CAROLINA

N.C. Alliance for the Mentally Ill, Inc.
3716 National Drive, Suite 213
Raleigh, NC 27612
Beth Morton, Project Director
(919) 783-1807
(800) 451-9682

OREGON

Family Support Work Group
Mental Health Association of Oregon
29980 Church Dr.
Shedd, OR 97377
Judy Rinkin
(503) 753-4135

PENNSYLVANIA

Parents Involved Network of
Pennsylvania, Inc.
311 South Juniper Street, Room 902
Philadelphia, PA 19107
Christina Corp., Project Coordinator
(215) 735-2465

TEXAS

Partners Resource Network, Inc.
6465 Calder, Suite 202
Beaumont, TX 77707
Janice Foreman, Executive Director
Charlotte Provencher, Project Coordinator
(409) 866-4726

VERMONT

Vermont Federation of Families for Children's
Mental Health
RD 2, Box 770
Morrisville, VT 05661
Judith A. Sturtevant, Project Coordinator
(802) 888-3231

VIRGINIA

Parent and Children Coping Together, Inc.
5001 West Broad Street, Suite 214
Richmond, VA 23230
Carol Obrochta, Parent Coordinator
(804) 285-3636

WASHINGTON, DC

Family Advocacy and Support
Association
3649 New Hampshire Avenue, NW
Washington, DC 20010
Velva Spriggs, President
(202) 708-2193

WISCONSIN

Wisconsin Family Ties, Inc.
16 North Carroll Street, Suite 410
Madison, WI 53703
Margaret Mezera, Executive Director
(608) 267-6888

* These organizations were funded by the National Institute of Mental Health (NIMH) in October, 1990.

Appendix D

Parent Training and Information (PTI) Projects

ALABAMA

Carol Blades
Special Education Action Committee, Inc.
P.O. Box 161274
Mobile, AL 36616-2274
(205) 478-1208

ALASKA

Judie Ebbert-Rich, Executive Director
P.A.R.E.N.T.S. TIP
P.O. Box 32198
Juneau, AK 99803
(907) 790-2246
Toll free in Alaska: 1-800-478-7678

ARIZONA

Mary Slaughter/Judie Walker
Pilot Parent Partnerships
2150 East Highland Avenue #105
Phoenix, AZ 85016
(602) 468-3001

ARKANSAS

Arkansas Parent Training Project
Bonnie Johnson
Arkansas Disability Coalition
10002 West Markham, Suite B7
Little Rock, AR 72205
(501) 221-1330

Barbara Semrau
FOCUS
2917 King Street, Suite C
Jonesboro, AR 72401
(501) 935-2750

CALIFORNIA

Joan Tellefson
TASK
100 West Cerritos Avenue
Annaheim, CA 92805-6546
(714) 533-TASK (8275)

Northern California Parent Training and Information Coalition (NCC)
Florene Poyadue
Parents Helping Parents
535 Race Street, #220
San Jose, CA 95126
(408) 288-5010

Pam Steneberg
DREDF
2212-6th Street
Berkeley, CA 94710
(415) 644-2555

Joan Kilburn
Disability Services Matrix
P.O. Box 6541
San Rafael, CA 94903
(415) 499-3877

COLORADO

Barbara Buswell/Judy Martz
PEAK
6055 Lehman Drive, Suite 101
Colorado Springs, CO 80918
(719) 531-9400

CONNECTICUT

Nancy Prescott
CT Parent Advocacy Center
P.O. Box 579
East Lyme, CT 06333
(203) 739-3089
1-800-445-2722 (CT only)

DELAWARE

Marie-Anne Aghazadian
PIC of Delaware, Inc.
700 Barksdale Road, Suite 6
Newark, DE 19711
(302) 366-0152

DISTRICT OF COLUMBIA

None

FLORIDA

Janet Jacoby
Parent Education Network of Florida
1211 Tech Boulevard, Ste. 105
Tampa, Florida 33619
(813) 623-4088

GEORGIA

Cheryl Knight
Parents Educating Parents, Georgia ARC
1851 Ran Runway, Ste 104
College Park, GA 30337
(404) 761-2745

HAWAII

Ivalee M. Sinclair
Hawaii Association for Child/Adults
with Learning Disabilities
200 N. Vineyard Blvd., Ste. 103
Honolulu, HI 96817
(808) 536-9684

IDAHO

Martha Gilgen
Idaho Parents Unlimited, Inc.
1365 North Orchard, #107
Boise, ID 83706
(208) 377-8049

ILLINOIS

Charlotte Des Jardins
Coord. Council for Handicapped Children
20 East Jackson Blvd., Ste. 900
Chicago, IL 60604
(312) 939-3513

Don Moore
Designs For Change
220 South State Street, Ste. 1900
Chicago, IL 60604
(312) 922-0317

INDIANA

Richard Burden
In•Source
833 Northside Boulevard, Bldg. #1, Rear
South Bend, IN 46617
(219) 234-7101
1-800-332-4433 (Indiana only)

IOWA

Carla Lawson
Iowa Exceptional Parents Center
33 North 12th Street
P.O. Box 1151
Fort Dodge, IA 50501
(515) 576-5870

KANSAS

Patty Gerdel
Families Together, Inc.
1023 Southwest Gage
Topeka, KS 60604
(913) 273-6343

KENTUCKY

Paulette Logsdon
Kentucky Special Parent Involvement Network
318 West Kentucky Street
Louisville, KY 40203
(502) 589-5717 or 584-1104

LOUISIANA

Debbie Braud, Project Prompt
United Cerebral Palsy of Greater New Orleans
1500 Edwards Avenue, Suite 0
Harahan, LA 70123
(504) 734-7736

MAINE

Deborah Guimont, (SPIN)
Special Needs Parent Information Network
P.O. Box 2067
Augusta, ME 04338
(207) 582-2504
1-800-325-0220 (ME only)

MARYLAND

Cory Moore, Director
Parents Place of Maryland
7257 Parkway Drive, Suite 210
Hanover, MD 21076
(301) 379-0900

MASSACHUSETTS

Artie Higgins
Federation for Children with Special Needs
95 Berkeley Street, Suite 104
Boston, MA 02116
(617) 482-2915
1-800-331-0688 (MA only)

MICHIGAN

Elmer L. Cerano
United Cerebral Palsy/Detroit Community Service Department
17000 West 8 Mile Road, Suite 380
Southfield, MI 48075
(313) 557-5070
Barbara Cardinal, Project Director
Edith Sharp, Project Coordinator

Sue Pratt
Citizens Alliance To Uphold Special Education (CAUSE)
313 South Washington Square
Lower level
Lansing, MI 48933
(517) 485-4084
1-800-221-9105

MINNESOTA

Marge Goldberg/Paula Goldberg
PACER Center
4826 Chicago Avenue South
Minneapolis, MN 55417
(612) 827-2966
1-800-53-PACER (MN only)
Fax (612) 827-3065

MISSISSIPPI

Anne Presley
Association of Developmental Organizations of Mississippi
332 New Market Drive
Jackson, MS 39209
(601) 922-3210 or
1-800-231-3721

MISSOURI

Missouri Parents Act-MPACT
Marianne Toombs, Director
1722W South Glenstone, Suite 125
Springfield, MO 65804
(417) 882-7434 (TDD)
1-800-666-7228 (MO only)

Beth Mollenkamp, MPACT
625 North Euclid, Room 405
St. Louis, MO 63108
(314) 361-1660

MPACT, c/o Carolyn Stewart
1115 East 65th Street
Kansas City, MO 64131
(816) 333-6833
(816) 333-2323

MONTANA

Katharin A. Kelker
Parents, Let's Unite For Kids
EMC/MCHC
1500 North 30th Street
Billings, MT 59101-0298
(406) 657-2055

NEBRASKA

Jean Sigler
Nebraska Parent Information Training Center
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Omaha, NE 68131
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NEVADA

Charlene Rogerson, Project Coordinator
Parent Connection
Nevada Technology Center
2880 East Flamingo, Suite A
Las Vegas, NV 89121
(702) 735-2922

NEW HAMPSHIRE

Judith Raskin
Parent Information Center
151A Manchester Street
P.O. Box 1422
Concord, NH 03302
(603) 224-6299
(603) 224-7005 (Voice/TDD)
Fax (603) 224-4365

NEW JERSEY

Diana Cuthbertson
Statewide Parent Advocacy Network, Inc. (SPAN)
516 North Avenue East
Westfield, NJ 07090
(201) 654-7726
(201) 654-SPAN (Voice/TDD)

NEW MEXICO

Randi Malach
EPICS Project
P.O. Box 788
Bernalillo, NM 87004
(505) 867-3396

Linda Coleman/Stella Shaw-Petti
Project Adobe
1127 University NE
Albuquerque, NM 87102
(505) 842-9045

NEW YORK

Joan M. Watkins
Parent Network Center (PNC)
1443 Main Street
Buffalo, NY 14209
(716) 885-1004

Norma Rollins
Advocates for Children
New York City Org./Special Ed.
24-16 Bridge Plaza South
Long Island City, NY 11101
(718) 729-8866

NORTH CAROLINA

Connie Hawkins
Exceptional Children's Assistance Center
P.O. Box 16
Davidson, NC 28036
(704) 892-1321

NORTH DAKOTA

Kathryn Erickson
Pathfinder Services of ND
Arrowhead Shopping Center
16th Street and 2nd Avenue SW
Minot, ND 58701
(701) 852-9426

OHIO

Margaret Burley, Ohio Coalition for the
Education of Handicapped Children (OCEHC)
Training Center:
933 High Street, Suite 106
Worthington, OH 43085
(614) 431-1307 Voice/TDD
Business Office:
1299 Campbell Road, Suite B
Marion, OH 43302
(614) 382-5482 Voice/TDD

Cathy W. Heizman
Child Advocacy Center
Lower Level
106 Wellington Place
Cincinnati, OH 45219
(513) 381-2400

OKLAHOMA

Sharon Bishop
Parents Reaching Out in Oklahoma Project
1917 South Harvard Avenue
Oklahoma City, OK 73128
(405) 681-9710; 1-800-PL94-142

OREGON

Cheron Mayhall
Oregon Cope Project
999 Locust Street, Northeast Box B
Salem, OR 97303
(503) 373-7477 (Voice/TDD)

PENNSYLVANIA

Gail Walker
Mentor Parent Program
Route 257 Salina Road
P.O. Box 718
Seneca, PA 16346
(814) 676-8615
1-800-447-1431 (PA only)

Louise Thieme, Director
Parent Eduction Network
240 Haymeadow Drive
York, PA 17402
(717) 845-9722

Christine Davis
Parents Union for Public Schools
311 S. Juniper Street, Suite 602
Philadelphia, PA 19107
(215) 546-1166

PUERTO RICO

Carmen Selles Vila
Asociacion De Padres Pro Biene Star/Ninos
Impedidos de PR, Inc. (APNI)
Box 21301
Rio Piedras, PR 00928
(809) 763-4664 or 765-0345

RHODE ISLAND

Linda Katz, Acting Secretary/Board of Directors
Rhode Island Parent Information Network
c/o R.I. Protection & Advocacy System (RIPAS)
55 Bradford Street
Providence, RI 02903
(401) 831-3150

SOUTH CAROLINA

Colleen Lee
PRO-PARENTS
3440 Harden Street Ext.
Columbia, SC 29223
(803) 737-6405

SOUTH DAKOTA

Nancy Nelson, Director
South Dakota Parent Connection
P.O. Box 84813
Sioux Falls, SD 57118-4813
(605) 335-8844

TENNESSEE

Carol Westlake
STEP
1805 Hayes Street, Suite 100
Nashville, TN 37203
(615) 327-0294

TEXAS

Janice Foreman - Partners Resource Network
PATH
6465 Calder Avenue, Suite 202
Beaumont, TX 77707
(409) 866-4726
(409) 866-4973 (TDD)

UTAH

Helen Post
Utah PIC
2290 East 4500 South, Ste. 110
Salt Lake City, UT 84117
(801) 272-1051; 1-800-468-1160

VERMONT

Connie Curtin/Joan Sylvester
VT Information And Training Network,
Vermont/ARC
37 Champlain Mill
Winooski, VT 05404
(802) 655-4016 (Voice/TDD)

VIRGIN ISLANDS

None

VIRGINIA

Winifred Anderson
Parent Education Advocacy Training Center
228 South Pitt Street, Ste. 300
Alexandria, VA 22314
(703) 836-2953

WASHINGTON

Heather Hebdon
PAVE/STOMP
Specialized Training of Military Parents
12208 Pacific Highway Southwest
Tacoma, WA 98499
(206) 588-1741

Martha Gentili
Washington PAVE
6316 South 12th Street
Tacoma, WA 98465
(206) 565-2266 (Voice/TDD)
1-800-5-PARENT

WEST VIRGINIA

Joyce Altizer
Coalition of Parents/Advocates, Inc.
4613 Sixth Avenue
Vienna, WV 26105
(304) 295-5435

WISCONSIN

Deborah Stamm
Parent Education Project
United Cerebral Palsy of SE Wisconsin
230 West Wells Street, Ste. 502
Milwaukee, WI 53203
(414) 272-4500
(414) 272-1077 (TDD)

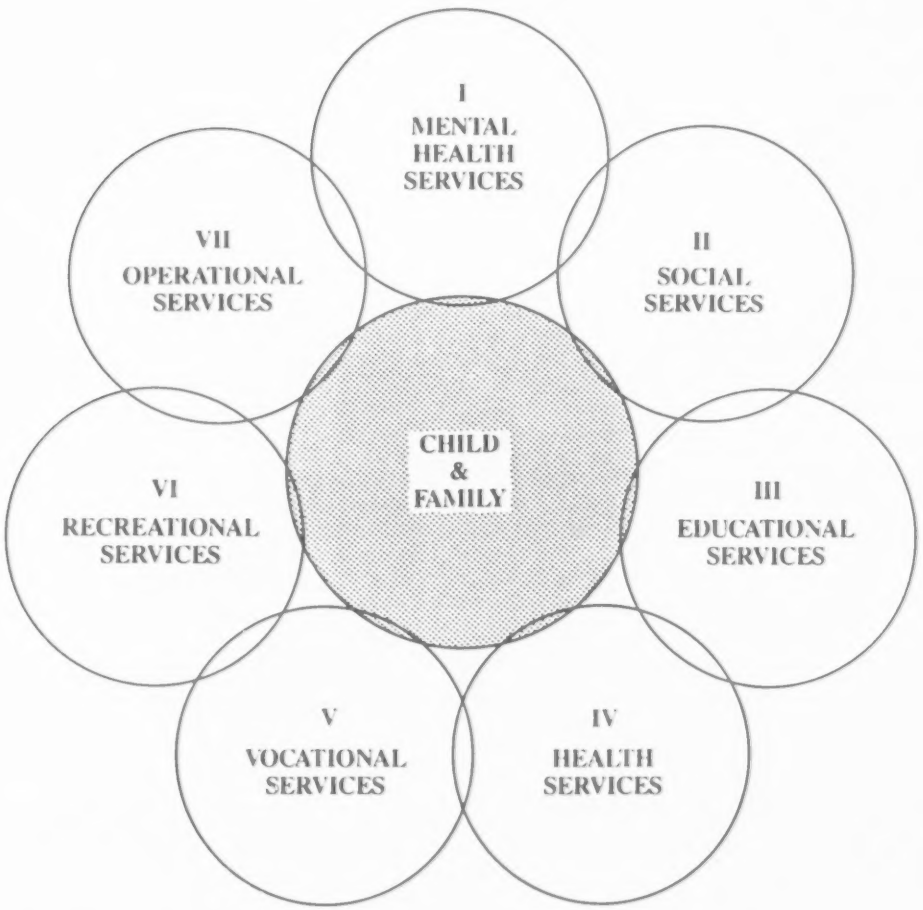
WYOMING

Terri Dawson, Executive Director
Wyoming PIC
(Parent Information Center)
270 Fort Street
Buffalo, WY 82834
(307) 684-5461

Appendix E
CASSP System of Care

The following information about the CASSP System of Care is taken from A System of Care for Severely Emotionally Disturbed Children & Youth (1986), written by Beth A. Stroul, M.Ed., CASSP Technical Assistance Center, and Robert M. Friedman, Ph.D., Florida Mental Health Institute, University of South Florida and published by CASSP (Child and Adolescent Service System Program of the National Institute of Mental Health). The following information is reprinted with permission.

SYSTEM OF CARE FRAMEWORK



VALUES AND PRINCIPLES FOR THE SYSTEM OF CARE

CORE VALUES FOR THE SYSTEM OF CARE

1. The system of care should be child-centered, with the needs of the child and family dictating the types and mix of services provided.

2. The system of care should be community-based, with the locus of services as well as management and decision-making responsibility resting at the community level.

GUIDING PRINCIPLES FOR THE SYSTEM OF CARE

1. Emotionally disturbed children should have access to a comprehensive array of services that address the child's physical, emotional, social and educational needs.

2. Emotionally disturbed children should receive individualized services in accordance with the unique needs and potentials of each child, and guided by an individualized service plan.

3. Emotionally disturbed children should receive services within the least restrictive, most normative environment that is clinically appropriate.

4. The families and surrogate families of emotionally disturbed children should be full participants in all aspects of the planning and delivery of services.

5. Emotionally disturbed children should receive services that are integrated, with linkages between child-caring agencies and programs and mechanisms for planning, developing and coordinating services.

6. Emotionally disturbed children should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner, and that they can move through the system of services in accordance with their changing needs.

7. Early identification and intervention for children with emotional problems should be promoted by the system of care in order to enhance the likelihood of positive outcomes.

8. Emotionally disturbed children should be ensured smooth transitions to the adult service system as they reach maturity.

9. The rights of emotionally disturbed children should be protected, and effective advocacy efforts for emotionally disturbed children and youth should be promoted.

10. Emotionally disturbed children should receive services without regard to race, religion, national origin, sex, physical disability or other characteristics, and services should be sensitive and responsive to cultural differences and special needs.

COMPONENTS OF THE SYSTEM OF CARE

1. MENTAL HEALTH SERVICES

Nonresidential Services:
Prevention
Early Identification & Intervention
Assessment
Outpatient Treatment
Home-Based Services
Day Treatment
Emergency Services

Residential Services:
Therapeutic Foster Care
Therapeutic Group Care
Therapeutic Camp Services
Independent Living Services
Residential Treatment Services
Crisis Residential Services
Inpatient Hospitalization

2. SOCIAL SERVICES

Protective Services
Financial Assistance
Home Aid Services
Respite Care
Shelter Services
Foster Care
Adoption

3. EDUCATIONAL SERVICES

Assessment & Planning
Resource Rooms
Self-Contained Special Education
Special Schools
Home-Bound Instruction
Residential Schools
Alternative Programs

4. HEALTH SERVICES

Health Education & Prevention
Screening & Assessment
Primary Care
Acute Care
Long-Term Care

5. VOCATIONAL SERVICES

Career Education
Vocational Assessment
Job Survival Skills Training
Vocational Skills Training
Work Experiences
Job Finding, Placement & Retention Services
Supported Employment

6. RECREATIONAL SERVICES

Relationships with Significant Others
After School Programs
Summer Camps
Special Recreational Projects

7. OPERATIONAL SERVICES

Case Management
Self-Help & Support Groups
Advocacy
Transportation
Legal Services
Volunteer Programs